APPENDIX 1 Summaries of Public Input and RSN Listening Sessions

WASHINGTON STATE MENTAL HEALTH TRANSFORMATION GRANT Public Testimony Summary and Analysis

ADULT CONSUMERS AND FAMILY MEMBERS SUBCOMMITTEE April 3, 2006

Introduction

The current report represents an analysis of the content of public testimony related to the Adult Consumers and Family Members Subcommittee of the Washington State Mental Health Transformation (MHT) effort. The report provides a summary of statements presented during the public testimony periods of Subcommittee meetings, as well as additional information received by the state MHT team determined by the research team to be relevant to this Subcommittee. These additional pieces of information include public comments received via email, fax, web survey, or handwritten statements, and also relevant feedback submitted from entire agencies or organizations, some of which engaged in their own group processes before compiling and submitting their input.

The analysis presented here also includes information received from other sources during the course of the MHT planning process, such as Regional Support Network (RSN) reports of priorities and transcripts from statewide MHT "Listening Sessions." Finally, statements provided in other Subcommittees' public hearings that were determined to be relevant to the Adult Consumers Subcommittee were included in this analysis.

Method

Across the many sources of data listed above, information received and analyzed typically were responses to a consistent set of 4 open-ended questions posed to individuals statewide:

- 1. Within Washington State, and for all mental health services, public or private, what is working well when addressing the needs of mental health consumers?
- 2. Within Washington State, and for all mental health services, public or private, what is NOT working, creates barriers or fails to provide quality service and support when addressing the needs of mental health consumers?
- 3. What would a "transformed" mental health system look like?
- 4. What outcomes would indicate that the changes in the mental health service systems are creating improved results for consumers?

Data were received from the state MHT team in the form of transcripts from Subcommittee meetings (created by a legal transcription service), reports from RSNs, emails and web surveys forwarded from public constituents, and Adobe Acrobat "PDF" files of handwritten testimony. A team of PhD-level researchers then conducted qualitative analysis of these raw data using a technique described by Marshall & Rossman (1989). First, unique statements were isolated and

summarized from all individual testimonials received. Next, categories were created and all statements sorted by these categories. Third, new categories were created for statements that did not fit the initial categories. Finally, small categories were sorted into primary categories.

Questions about this report can be directed to:

Eric J. Bruns, Ph.D., University of Washington Division of Public Behavioral Health and Justice Policy ebruns@u.washington.edu - 146 N. Canal Street, Suite 100, Seattle, WA, 98107 - 206-685-2085

To increase ease of use and interpretation, a single analysis of all statements was conducted. The information presented here combines responses to all four questions into a single summary of all testimony received. The purpose of the report is to provide Subcommittee members and others working on the MHT project a record of all the public feedback received that is relevant to this Subcommittee, organized in a way that allows for observation of the relative amount of testimony provided within each topic area, and discussion of priorities for action.

The current report

The current report consists of three main sections.

- The first section presents an **overview** of the analysis, including data sources and total number of unique statements coded. This section also includes a brief narrative summary of the findings.
- The second section presents the **results of qualitative analysis in detail**. This Table presents unique themes expressed in public testimony, organized by primary and secondary categories. For each unique theme, the number of statements that were found in the data related to that theme is presented. It is hoped that this Table will be a useful reference for the Subcommittee as it reviews the priorities presented by the public for action.
- The third section presents a selection of **direct statements and quotes** from the meeting transcripts and other information received, grouped by major themes.

Acknowledgments

Data analysis for the Mental Health Transformation Public Testimony Summary and Analysis Reports was conducted by:

Suzanne E. Kerns, PhD ABD, Eric J. Bruns, Ph.D., Phoebe Mulligan, and Justin D. Smith, University of Washington Division of Public Behavioral Health and Justice Policy Maria Monroe-DeVita, Behavioral Tech Research, Inc.

Sabina Low Sadberry, Ph.D., University of Washington Evans School of Public Affairs

WASHINGTON STATE MENTAL HEALTH TRANSFORMATION GRANT Public Testimony Summary and Analysis ADULT CONSUMERS AND FAMILY MEMBERS SUBCOMMITTEE

Data sources:

- 1. Public Testimony at the Adult Consumer and Family Subcommittee Meeting, SeaTac Holiday Inn, 2/9/06
- 2. Public Testimony at the Adult Consumer and Family Subcommittee Meeting, Eastern State Hospital, 2/13/06
- 3. Data transferred from the first two Children/Youth and Parents/Families Subcommittee Meetings, Highline Community Health in Burien, 2/7/06, and at the Everett Library, 3/1/06
- 4. Department of Health (DOH) Response to the Four Questions, 3/24/06
- 5. Additional written submissions from individuals, agencies, and organizations statewide

Total Statements coded = 167

Summary of findings

Public testimony relevant to the Adult Consumers and Family Members Subcommittee consisted of 167 unique statements coded from 36 individuals who gave testimony at public hearings (or written submissions) as well as additional documents submitted from individuals, agencies, and organizations. These 167 statements were sorted into 12 main categories or themes. The two categories into which the most statements were coded (35 statements each) were: (1) maintaining a focus on recovery and consumer-driven care, and (2) vocational training, employment, and education. Other major themes included using evidence-based practices and improving the effectiveness of services (27 statements), concerns about hospital-based care (15 statements), and workforce development and provider training issues (13 statements). Additional categories included providing financial assistance, medication, funding issues, health disparities, and transportation. Ten respondents also stated specific adult consumer and family member outcomes that should be focused upon and tracked. A summary of these results is presented below.

Major Theme #1: Vocational Training, Employment, and Education

Half of all respondents reported that vocational training, employment, and education are essential components of a transformed mental health system. The majority of these respondents reported that persons with mental illness are in great need of better vocational training/rehabilitation in order to obtain employment in the community. In particular, respondents cited the need for the Division of Vocational Rehabilitation (DVR) to employ specialists who have been trained to work with persons with mental illness. One recommended way to achieve this was to integrate or shift funding from DVR to the Mental Health Division (MHD).

Respondents further cited the need for continuing to support the Clubhouse model (specifically referencing Evergreen Club in Spokane and Rose House in Tacoma) and implementing more supported employment programs statewide. Respondents further reported that employment opportunities are half the battle in achieving positive vocational outcomes. In particular, they reported the need for a range of employment opportunities -- from competitive employment with

fair wages to "meaningful employment" that provides the consumer with both the choice of job as well as support on the job. This range in employment needs and goals has implications for employers who may not have experience in working with persons with mental illness or an understanding of mental illness, and may provide an important opportunity for consumer providers (i.e., peer or recovery specialists) to fill these important roles (see also recommendations under Recovery and Consumer Involvement). Finally, respondents reported that opportunities for obtaining various types of education goals, particularly in a supported environment, are crucial for recovery (e.g., the SEER Program in Spokane).

Major Theme #2: Evidence-Based Practices and Improving Services

Nearly half of all respondents reported that a transformed mental health system should focus on implementing evidence-based practices (EBPs) and improving service approaches for adult consumers and their families. Among these, most respondents reported the need for more support and psychoeducation programs for consumers and families (e.g., NAMI's Family-to-Family program, illness management, a peer mentoring program in the State of Alaska). The same percentage of respondents also reported the need for more psychotherapy or counseling services available in both community mental health centers and the state hospital. This theme further overlaps with one of the themes listed below related to the need for more clinical training for providers, particularly case managers (see Workforce Development and Provider Training). Respondents further reported that more psychiatric rehabilitation programs (e.g., skills training) are needed and described strengths and weaknesses related to current assessment practices in Washington. Related to assessment concerns, while practices such as the Behavior Risk Factors Surveillance System (BRFSS) are reportedly "working" in the state, respondents reported that more attention to an integrated approach, including assessment of physical and mental health, is needed. Other minor themes in this area included the need for more crisis and acute services, as well as prevention programs. Respondents indicated the need to make sure to individually tailor services, as well as include promising and emerging practices.

Major Theme #3: Recovery and Consumer Involvement

In line with the vision of the Mental Health Transformation Grant, many respondents reported that both recovery and consumer involvement will be critical components of a transformed mental health system. Among the top responses within this category were consumer voice and choice in treatment (e.g., more say in who they see and the types of therapy are available) and the need for mental health providers to incorporate recovery into their current practices (e.g., moving beyond simply wanting symptom stabilization without attending to larger life goals defined by the consumer). The vision for a consumer-driven mental health system was also reported, including the need for consumers to be more involved as providers as well as in policy and administrative roles. Many respondents reported concerns about consumer rights, including the extent to which they are informed about the services they are receiving and the extent to which they can share their concerns without negative implications within their treatment.

Major Theme #4: Workforce Development and Provider Training Issues

The need for workforce development and better provider training was reported by a number of respondents. In particular, respondents reported that there is little education or practical training within undergraduate and some graduate programs, particularly in working with the complex and diverse needs of persons with mental illness. Suggested avenues to improve this area included

state certification through the U.S. Psychiatric Rehabilitation Association (which requires provider demonstration of competence in this area), as well as better classroom instruction and specific training at both the Bachelor's and Master's levels in working with persons with mental illness in the community. Other workforce development issues included concerns about staffing shortages and the need to train police and correctional staff to work with people with mental illness.

Major Theme #5: Financial Assistance

About a quarter of respondents reported that financial assistance is essential for consumers. It is a basic need that – without its presence – makes recovery very difficult. Respondents cited the need for consumers to have money to pay for their medications, as well as personal income and/or benefits to pay for personal needs.

Major Theme #6: Specific Concerns within Eastern State Hospital

Since one of the two Adult Consumer and Family Subcommittee Meetings was held at Eastern State Hospital, several respondents provided feedback specific to this service setting. This feedback can be divided between those related to treatment within the hospital and those related to transitioning out of the hospital to the community. Concerns within the hospital include limited activities on the unit, prescriptive programming (without individualized services), and concerns that staff have too much paperwork which takes them away from direct care. One respondent reported that there was a need to get more assistance with advocacy and arbitration. Another respondent reported that sometimes consumers are placed at ESH because there weren't any beds open closer to their homes, which has many implications in terms of ongoing support from family or assistance with disposition.

Feedback regarding transition from the hospital to the community included the need for a better disposition planning process and limited resources in the community (e.g., not enough transitional programs, need for more independent and supported housing).

Other Major Themes

Transportation, Funding, Medication, and Health Disparities

Several respondents reported that each of these four areas need improvement. Regarding transportation, respondents reported that the public transportation system is inefficient and unavailable in many places.

Funding concerns focused on the system as a whole, as well as specific programs (e.g., SEER program, congregate care, Evergreen Club). Respondents also reported concerns about the state focusing on funding toward short-term vs. long-term solutions.

Medication concerns included worries about overmedication as well as the effectiveness and side effects of the new atypical antipsychotics. There were also concerns about the mental health system's focus and resources devoted to medications vs. other forms of treatment.

Regarding health and mental health disparities, respondents reported concerns about the fact that people with mental illness have disproportionately higher rates of tobacco use. Furthermore, one

respondent noted concern that while health disparities keep getting brought up in many venues, it always gets lost in the shuffle of priorities.

Consumer and Family Outcomes

A few respondents provided feedback specifically on important consumer and family outcomes, with a total of 10 statements provided in this area. Suggested outcome areas included decreased hospitalization, decreased incarceration, reduced substance use, decreased tobacco use, stable housing, better transportation, and stable employment. In addition, there were recommendations to further measure the percentage of consumers working as providers (target = 50%) and the percentage of consumers working at the policy level. One respondent suggested making sure that the system use an outcome measure that can't be manipulated to look like people are improving when actually they are getting poorer results every year.

A full summary of all themes and statements within each theme is presented in the Table on the following pages.

Table 1.
Results of qualitative analysis of public testimony for the Adult Consumers and Family Members Subcommittee (N=167 statements total).

Themes	N Statements
Recovery & Consumer Involvement	35
Consumer-Driven System and Services	12
Need consumers working at the policy and administrative levels/ being politically active	4
Need consumers working as providers/ Consumer-operated services (e.g., Peer to peer programs, peer recovery specialists)	3
Need a formal venue where consumers can express what's going well/not going well in their treatment	2
Consumer-driven aspect of the Transformation Grant is a positive step in the right direction	1
Consumers are an underutilized resource and knowledge-based technical assistance base	1
DVR should hire consumers and recovery specialists	1
Providers Incorporating Recovery into Practices	8
Many providers focus on more basic goals in treatment, rather than helping the individual achieve recovery	3
Need more compassionate treatment/respect for consumers	3
Some pockets of providers really "get" recovery and are transforming their work to promote this model	1
"Warehousing" in state hospitals with little emphasis on recovery	1
Consumer Voice/Choice in Services	7
Consumers don't feel that they are "heard"	5
Consumers should have more say in who they see and what types of therapy are available to them	2
Consumer Rights	6
Need better informed consent process	2
Society and providers treat consumers like they don't have any rights	2
Consumer concerns that what they say will be held against them	2
Expanding definition of recovery	2
The definition of recovery should not just be about living with the fact that you haven't fully recovered	1
We need to promote the concept of interdependence as well as independence	1
Vocational Training, Employment, & Education	35
Vocational Training/Rehabilitation	12
More vocational training/support is needed	9
Need DVR specialists who know how to work with people with mental illness	2
Integrate/shift funding from DVR to MHD to better assist with skill building in employment	1
Employment Opportunities	8
Job placement in the community can be difficult due to some consumers' history	3
Need more emphasis on competitive employment/fair wages for employment	3
Need more meaningful employment for people with mental illness however that is defined for each person	1
Need partnerships with businesses for placing consumers in jobs and developing	1

vocational skills	
Clubhouse Model	7
Clubhouses are working well	4
Evergreen Club (run through Spokane Mental Health) is a good clubhouse program	2
Rose House is a good clubhouse program/ should be replicated across the state	1
Education	6
Need more supported/supportive education	4
SEER Program is excellent	2
Supported Employment	2
Community supported employment is needed to make clubhouses work	1
I believe in supported work/employment	1
Evidence-Based Practices (EBPs) and Improving Services	27
Support/Psychoeducation for Consumers and Families	7
More supports/education for families	4
Need more education of consumers about their own illness/ wellness management programs	2
Need mentoring program like they have in Alaska pairs a person with MI with a brother or sister in the community for doing outings, work programs, etc.	1
Psychotherapy & Counseling Services	7
More counseling and therapy services	6
More support groups for depression	1
Psychiatric Rehabilitation	3
More psychiatric rehabilitation / skill-building to increase capacity to be independent	2
Need more help with dealing with issues around relapse, symptom management, and medication management	1
Prevention & Early Intervention	3
Early Intervention Program (for HIV clients) is working well (see specifics in DOH doc 3/24/06)	1
First Steps provides important services to pregnant and postpartum adult females	1
More prevention programs to prevent harmful, dangerous situations for consumers living in the community	1
Assessment	3
Need more holistic or integrated approach to assessing mental and physical health	2
The Behavior Risk Factors Surveillance System (BRFSS) is working well assesses mental health, anxiety, and depression	1
Crisis & Acute Services	2
Acute treatment unit/something between community and hospital is needed	1
Need crisis lines	1
Considerations for Conceptualizing and Implementing EBPs	2
Expanding definition of EBPs (e.g., promising, emerging) will increase room for innovation	1
More individualized approaches to all services	1
Eastern State Hospital Concerns	15
Concerns With Transitioning from Hospital to Community	9
Better disposition planning from state hospital	4

Not enough community and transitional programs to connect someone discharged from state hospital (p. 84, 2/13)	3
More independent and supported housing options are needed	1
Difficulty with transitioning to the community when the person is hospitalized far from home	1
Needs Within the Hospital	6
Limited activities on unit	2
Prescriptive programming	1
Too much paperwork takes unit staff away from client care	1
Need the ESH ombuds and more help in advocating/arbitrating for consumers	1
Placement at ESH because there weren't any beds open closer to the person's home little support for the consumer	1
Workforce Development/Provider Training	13
Education and Training for Community Providers	9
People coming into this field need better education and training	7
Education of providers should start in the classroom, beginning with practical learning at the bachelor's and master's levels	1
Certification process through the U.S. Psychiatric Rehabilitation Association would ensure provider competencies	1
Other Workforce Development Issues	4
Staffing shortage	2
Need training for police force/ Corrections in working with persons with mental illness	2
Financial Assistance	10
Need more personal income/benefits	5
More assistance with paying for meds	4
Information to take "default" status off student loans due to mental illness/improve credit	1
Adult Consumer and Family Outcomes	10
Percentages of people employed	2
Decrease in hospitalizations	1
Substance use decreases	 1
More stable housing, transportation	1
Percentages of consumers employed as providers (target = 50%)	1
Percenrage of consumers working at the policy level	1
Tobacco use rates among people with mental illness decrease	1
Decrease in incarcerations	1
Make sure you use an outcome measure that can't be manipulated to look like people are improving when actually they are getting poorer results every year	1
Medication	6
Overmedication is a problem	3
The newer atypical antipsychotics don't necessary have a better profile in terms of side effects than the older medications	1
Many people do better and eventually recover without antipsychoatic medications	1
We're spending hundreds of millions of dollars on medications, leaving little for other resources	1
Funding Issues	5
Limited funding/resources in the system	2

Problems with cutting funding for quality programs (e.g., SEER)	2
We spend our money on short-term vs. long-term solutions	1
Health disparities among people with mental illness	3
Cigarette/tobacco use is problematic	2
Health/mental health disparities are a problem	1
Transportation is a problem	3
• • • • • • • • • • • • • • • • • • •	
Other Responses	5
	5
Other Responses	5 1 1
Other Responses Parity law is a good thing	5 1 1
Other Responses Parity law is a good thing Paperwork barriers	5 1 1 1

WASHINGTON STATE MENTAL HEALTH TRANSFORMATION GRANT Public Testimony Summary and Analysis ADULT CONSUMERS AND FAMILY MEMBERS SUBCOMMITTEE

Selected Representative Quotes

Major Theme #1: Vocational Training, Employment, and Education

Needing DVR specialists who know how to work with mental illness:

"...not to pick on DVR, but there's a big problem in delivery of services in helping people with psychiatric disabilities get employment. They have a low percentage of people get jobs and maintain jobs and part of it is that DVR workers aren't well trained in how we work with people with psychiatric disabilities (p. 66, TWG Subcommittee, 2/9/06).

Evergreen Club is a good clubhouse program:

"Now, that's another job training program for people from mental health. That's an excellent program for people. I was there for three years. I got two jobs; a Pepsi Company job. I was helping a Pepsi Company guy. I was getting paid minimum wage. I was giving pop and helping him put pop in the truck. He gave me a small paper route" (p. 23 TWG Subcommittee, Feb. 13, 2006).

Job placement in the community can be difficult due to some consumers' history -- Need more jobs that do not discriminate because of this factor:

"I have a college degree...Can I go out there and get a job because I've been out sick for two years or two and a half years? I doubt it. And I got 20 years of experience turning wrenches on cars. Could I get a job in the automotive field? Not a chance in your lifetime, let alone my own" (pp. 128-129, TWG Subcommittee Meeting, February 13, 2006).

Need more emphasis on competitive employment/ fair wages:

"...jobs provided for consumers with pay – not 50 cents an hour, like we used to get – would provide realistic incentive for consumers to participate" (p. 20, TWG Subcommittee, February 13, 2006).

The Support Education Enhancing Rehabilitation (SEER) program (in Spokane) is a good supported education program:

"It helps persons with mental illness integrate either into the work world or into the academic environment...it has been very beneficial for people to get integrated into the community and get their GEDs and all sorts of stuff. There's a transition-to-college program...a basic adult education program and all sorts of programs that help different types of persons with mental illness get their needs met in a very supportive environment (p. 28, TWG Subcommittee, February 13, 2006).

Major Theme #2: Evidence-Based Practices and Improving Services

Consumer and Family Support/Psychoeducation:

"...Family-to-family, which, I think, of course, being a NAMI person, I think is excellent. Support groups that we have through NAMI for families, and also for the consumer and their particular need, whether they're bipolar, schizophrenic, whatever, we have support" (p. 35 TWG Subcommittee, February 13, 2006).

"I think there should be more therapy for mental health" (p. 23, TWG Subcommittee, February 13, 2006).

Major Theme #3: Recovery and Consumer Involvement

Need better informed consent:

"...informed consent (is) not present in your current mental health system. Clients are not adequately informed to the consequences of treatments. They're not informed of the alternatives available..." (p. 85, TWG Subcommittee Meeting, February 9, 2006)

Providers aren't helping consumers to move into recovery

"I think that people don't really have an appreciation for how to help people really maintain and move into recovery after they're leaving this hospital...If a person has moved beyond (relapse, symptom management, medication management), I don't feel like people know how to really support a person in their next steps of recovery" (p. 82, TWG Subcommittee Meeting, February 13, 2006).

"...I also believe there's a problem with a lack of positive expectations from case managers...Just stabilizing people is enough for a lot of case managers and when consumers will come and say 'I want to go to school, I want a job...I want a house,' that they'll say we don't want to set you up for disappointment, so lower your expectations so that doesn't work" (p. 67, TWG Subcommittee Meeting, February 9, 2006).

Venues where consumers can express what's going well/not going well in their tx

"In Napa, California, they have self- self-government, both California and Arizona both. They have – the patients elect a president and they have meetings where they...They express what they think should be done and should be done and stuff, and it works very well. I was on the Director's Advisory Council" (p. 118, TWG Subcommittee Meeting, February 13, 2006)

More consumers working as providers and helping with implementation

"I would see that as a very under-used resource and knowledge-based technical resource, technical assistance base. Whether that's for starting up clubhouses, starting up drop-in centers, educating the public, educating the police, technical assistance to a consumer-run system" (p. 93, TWG Subcommittee, February 9, 2006).

"...and I learned this from the supported education teacher because she was a consumer. And that's why I say consumers need to be hired. They need to be working in mental health centers. She's the only one I would have learned it from. A case manager could tell me until she's blue in the face 'you can recover' or 'you can get up,' but I needed to hear it from somebody who had done it" (p. 70, TWG Subcommittee Meeting, February 9, 2006).

"I would like to see peer recovery specialists and we're looking at training some that are employed in mental health centers and state hospitals and other agencies at a competitive wage with the same status and stature of case managers" (p. 67, TWG Subcommittee Meeting, February 9, 2006)

Need more consumers working at the policy level/getting politically active

"I'd like to see a lot more policymakers with mental illnesses sitting at the table and I'd like to see them (get the) support to get their graduate degree so they can have the qualifications (and) that nobody can say 'you're not qualified.' I'd like to see them sitting at that table" (p. 71, TWG Subcommittee Meeting, February 9, 2006).

Major Theme #4: Workforce Development and Provider Training Issues

Provider education and training:

"...I work with WSU and EWU, and I would say that in terms of – some of the concerns about case managers and therapists, for persons who are leaving Eastern State Hospital, I'm not sure that we are doing a really good job of really training and teaching people who are coming into the field about – to have the kinds of skills that are really needed and are really current...students that are coming into the field don't have the practical skills that they need to be able to do the work. And you, as consumers, probably know that" (pp. 82-83, TWG Subcommittee Meeting, February 13, 2006).

"I work with a lot of students who don't get it. They don't get this, and they end up working in mental health, and they do the best they can, and they're very compassionate people, but they have to kind of figure it out on their own, read a lot on their own. It's not something they're grounded in when they walk into the field" (p. 87, TWG Subcommittee Meeting, February 13, 2006).

Certification process through the U.S. Psychiatric Rehabilitation Association would ensure provider competencies

"They have a certification process, which means that not only do you have to have a degree from a discipline, but you also have to be certified to work in psychiatric rehabilitation, which means you have to have X number of hours. You have to actually take a test. You have to demonstrate your competencies" (p. 86, TWG Subcommittee Meeting, February 13, 2006).

Major Theme #5: Financial Assistance

"Definitely putting a little money on the release, not just the treatment -- or with medications; assistance in helping them continue to pay for their medications" (p. 14, TWG Subcommittee, February 13, 2006).

Major Theme #6: Specific Concerns from Eastern State Hospital

We need more congregate care facilities and beds to support transition from hospital to community

We need help with and more of a focus on finding *independent* living (not just board-and-care, group homes) after discharge.

Other Themes

Transportation

"I have received quite a few complaints about the Paratransit setup; the way it is, too, with making people doing routes in, like, groups of people where people are left sitting for hours waiting for their ride, even though their class may be done" (p. 31, TWG Subcommittee Meeting, February 13, 2006)

WASHINGTON STATE MENTAL HEALTH TRANSFORMATION GRANT Public Testimony Summary and Analysis

CHILDREN, YOUTH AND FAMILIES SUBCOMMITTEE April 17, 2006

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Sabina Low Sadberry, Ph.D., University of Washington Evans School of Public Affairs

WASHINGTON STATE MENTAL HEALTH TRANSFORMATION GRANT Public Testimony Summary and Analysis CHILDREN, YOUTH AND FAMILIES SUBCOMMITTEE

Data sources:

- 6. Transcript of subcommittee hearing #1: Feb. 6th, 2006 (Burien, WA)
- 7. Transcript of subcommittee hearing #2: March 1st, 2006 (Everett, WA)
- 8. Transcript of subcommittee hearing #3: March 13th, 2006 (Wenatchee, WA)
- 9. 41 additional written documents from individuals, agencies, and organizations statewide

Total Statements coded = 682

Summary of Findings

Public testimony relevant to the Children, Youth, and Family Subcommittee consisted of 682 unique statements coded from 97 individuals who gave testimony at public hearings and 41 additional documents submitted from individuals, agencies, and organizations. These 682 statements were sorted into 11 main categories or themes. The category into which the most statements (186) were coded was commentary about existing services or service types, followed by a second category (with 84 additional statements) related to the desired outcomes of a transformed system. Funding (73 statements), availability of services (73 statements), continuity of care (60 statements), training and education (50 statements), Foster Care issues (39 statements), and family support issues (32 statements) also were major themes. Other themes included administrative concerns, transitions for youth, and early intervention. Discussion of each of these themes is presented below.

Information about current programs (Including statements about services that are working well, services we need more of, considerations for Evidence Based Practice, additional considerations, administrative concerns, and cultural diversity)

- ? Wraparound was the program most often named as a successful program that should be expanded. Additionally, there is a significant lack of day treatment options available. Parents are finding they have only 2 choices: inpatient hospitalization or inadequate weekly counseling sessions.
- ? Many folks brought up the importance of using evidence-based practices (EBP's), although with several stipulations. First, there must be consideration to the "whole person", not just their disorder. This includes sensitivity to issues of cultural and sexual diversity.
- ? A transformed system would provide services in the communities where people live and use therapeutic techniques that are appropriate and valid for presenting concerns. Services would be delivered at various levels of need, ranging from primary prevention to crisis and everywhere between. Clinicians would have a minimally sufficient amount of paperwork and administrative considerations. All programs would be culturally sensitive and relevant.

Effectiveness of interventions and services (Primary prevention, integration within primary care, general lack of effectiveness, additional considerations)

- ? The current system places the majority of emphasis on crises often waiting until it is too late to do effective intervention.
- ? A transformed MH system would put the preponderance of support in prevention and early intervention. MH services would be fully integrated within primary care. A transformed system would not require diagnostic labeling to receive services and significant efforts would be put forth to reduce stigma associated with mental illness.

Funding (Including managed care, program funding, and staff pay)

? A transformed system would have funding available to pay for services for all kids. Care would not be dependent on the type of insurance available for the individual family. Mental health staff would be compensated at a higher level (will help reduce staff turnover which benefits clients and agencies). Flexible funds would be available to facilitate community-level work – including funding for transportation and community-based recreation.

Continuity of care (e.g., agency collaboration and mechanisms for continuity)

- ? Many people noted that there are significant fractures between agencies at multiple different levels. "Turf" wars and a "silo" mentality prevent continuity across and between services.
- ? A transformed system would consist of reliable partnerships across multiple systems accessed by youth (school, community, juvenile justice, families). Money would follow the kid as opposed to being "owned" by the providing agency.

Availability of services

- ? The biggest issue pertaining to availability of services is that the largest amount of services are available for Medicaid-eligible kids. Respondents indicated that there is very little available for kids whose families are not eligible for Medicaid but who do not have private insurance (working poor).
- ? A transformed system would have services available at multiple access points (e.g., primary care, school, community, more formal MH centers, juvenile justice, etc) and services would be available for all who are in need, regardless of insurance situation.

Family support

- ? Families of children with MH issues are in need of support. The way the current system is set up, a child/youth must be in crisis before often much-needed respite services can be activated.
- ? In a transformed system, parents, siblings, and other caregivers will be educated about their child's (or brother/sister's) mental health issues and have support networks available and easily accessible.

Training

- ? The most significant training issue is that those folks who are on the front-lines with children and youth (e.g., teachers, police officers, primary care docs) are not well trained for managing and treating mental health problems.
- ? A transformed system would have trained service providers outside of the traditional MH roles (counselors, psychologists, social workers, psychiatrists).

Foster care (Including Training and access)

- ? Overall, the current foster care system is not meeting the needs of foster kids across several levels. There are problems with access to foster care, discontinuity across placements, and availability of appropriate services.
- ? A transformed system would spend money up front to train foster parents and direct service personnel on the unique needs of foster care kids. Great attention would be placed on issues of placement and service continuity (so kids don't have to change service providers if they change placements).

Transitions (into, out of, and between placements)

- ? One very sad reality is that sometimes, for kids to become eligible for services, parents must give up their parental rights and turn their children over to DCFS.
- ? The way the confidentiality laws are currently written, parents of teens over the age of 13 may not be privy to therapy plans or transition plans after their teen leaves a hospital.
- ? A transformed system would involve parents/caregivers at all levels of intervention. Children/youth would be able to seamlessly access and float between services that are minimally sufficient to meet their needs. Caregivers directly responsible for managing a youth will be given adequate information to facilitate provider-family partnership in treatment of MH disorders (recognizing that treatment does not just happen at the clinic)

Desired outcomes (Child and family-level, provider level, system level)

? Mentioned most frequently: increased perception of availability of services, fewer kids entering into the juvenile detention, improved school performance, and restoration to more normative development (including full integration back into community).

A full summary of all themes and statements within each theme is presented in the Table on the following pages.

Table 1.
Results of qualitative analysis of public testimony for the Children, Youth, and Families Subcommittee (N= 682 statements total).

Themes	N Statements
Types of Services/Service Characteristics/Programs	186
More of These Types of Services are Needed	80
Day Treatment Programs	13
Home-Based/In-Home Care	9
Need More Counselors/Mental Health Professionals (other than psychiatrists)	8
Need Greater Availability of Psychiatrists	6
Adolescent Services/Beds in Hospitals/Inpatient Care	7
Programs for Co-Occurring Disorders	5
Emergent Beds for Kids/Adolescents	5
Emergency Mental Health Assessments	4
Simply Not Enough Services in Some Areas	3
Community-Based Behavior Therapy	3
Respite Care	2
Preschoolers and Kindergartners Expelled Too Often for Behavior Problems	2
Housing Options	2
Child and Teen Therapeutic Schools	2
Peer-to-Peer Programs	1
Age-Appropriate Group Homes	1
More Mental Health Assistance in the Juvenile Justice System	1
Adolescent Diversion Plan	1
Counseling for Sexually Abused Children	1
Programs for Our Returning Military and their Families	1
Wraparound More Available	1
Crisis Intervention	1
Zero Programs for Schizophrenic Kids	1
Additional Considerations	39
Diversion from Hospitals and Juvenile Detention When Mental Illness Happens	6

Individualized/Tailored Treatment for Each Child	4
Need Better Diagnoses	4
Overmedication Without Side-Effect Monitoring/Experimenting	3
Adult Model of Care Not Appropriate for Children	3
Child Needs to Have a Voice	2
Strength-Based Delivery	2
Client-Centered Approach	2
Increased Value Placed on Family and Consumers Input	2
Limited Number of Providers Who Can Address Both Child and Parent Mental Health Needs	2
Don't Want to Have to Use Counselors in Training but they are Often the Only Ones with DSHS	1
Some MH Agencies Do Not Strive for Reunification/Permanency but Rather Try to Keep Child in Their Service	1
Personal Values are Put Ahead of Good Science Too Often	1
For In-Home Care Providers, Consideration to Travel Time Important	1
Increased Accountability Due to Legislative Actions Working Well	1
Need Developmental Perspective for Crisis Management	1
Consideration of Disaster Plans Regarding Medication Management	1
Children in Hospitals Not Working - (does not address the family at all)	1
Mechanism for Parents to Defend Themselves if Child Accuses - Don't Just Take the Kid Away	1
Services that are working well	33
Dedicated and Skilled Mental Health Counselors	10
Wraparound is Positive Program	7
Advocacy Client System Working Well	2
Head Start and Early Head Start Working Well	1
YWCA Mental Health Counseling Working Well	1
West Gate Chapel Working Well	1
Pathways for Women Working Well	1
Intensive Family Preservation Services Working Well	1
Peer Groups for Kids Working Well	1
Parent Support Groups that Meet Regularly (something working well)	1
raioni Support Groups that most regularly (combining working work	
Mental Health Services Reach Kids in Juvenile Detention	1

Child is Informed About Their Treatment	1
Shared Children's Program Working Well	1
Madonna School Working Well	1
Children's Administration Working Well	1
Crisis Lines Working Well	1
Considerations for Evidence Based Practice's	18
Holistic as Well as Using an EBP	5
Support use of Scientifically Validated Programs	4
Expertise in the State Around EBP's	4
Need Better Integration from University-Based EBP's	2
EBP Reports Should be Disseminated to Public	1
Should Be Allowed to Choose Non-EBP Care	1
State Wants EBP's but Doesn't Understand the Costs Associated and Won't Fund Them	1
Cultural Awareness	16
No/Limited Multicultural Program in the Community and Few Ethnically Diverse Staff	7
State Not Acknowledging Differences in Providing Rural Care	7
Good Access to Culturally Diverse Providers (esp. Spanish speaking)	2
Desired MH outcomes	84
Services and Programs	46
Availability of Appropriate Services	17
Timeliness to Access of Service/Getting Into The System	9
Shorter Length of Stay	2
Better Integration of Services	2
Availability of EBP's	2
Feedback Loop with Consumer Input	2
Evidence That True Provider-System Partnerships Have Been Formed	1
Evidence That True Provider-System Partnerships Have Been Formed Employment of Youth and Families at Local Agencies	1
·	-
Employment of Youth and Families at Local Agencies	1
Employment of Youth and Families at Local Agencies Faster Treatment Processes and Outcomes	1

Mutual Respect Between Services/Providers/Administration/Clients	1
State Determined Outcomes Carried Out by Local RSN's and Services	1
Greater Respect Given to Mental Health Providers	1
Comprehensive Services for Youth in Crisis	1
Increased Screening and Appropriate Referrals	1
Higher Job Satisfaction for Service Providers	1
Client-Related	38
Fewer Kids in Juvenile Detention	7
Restoration of Normative Development	5
Reduction in Hospital/In-Patient Visits	5
Family Functioning Higher after Treatment	4
Improved School Performance/Attendance	4
Decreased Substance Use	2
Reduction in Behavior Problems in School	2
Increased Satisfaction with Services	2
Less Family Homelessness	1
Greater Self-Confidence	1
Reduced Disparities in School Readiness	1
Fewer Infants Placed in Foster Care	1
Increased Community Engagement	1
Family Has Better Understanding of How to Help the Child	1
Get Kids Out of Foster Care and Back to "Normalcy"	1
Funding	73
Funding Limitations	38
Flexible Funding Options Needed - Too Many Restrictions Between Services/Agencies	12
Medical Insurance for All Kids Who Need It	7
Integrated Funding	6
Siloing or Departmentalized Funding Not Working	3
Need Social Commitment to Pay for Mental Health Services for All Kids, Including Homeless Kids	2
Money Should Follow the Kid	2
Need Subsidized Funding for Working Poor	1

If Both Parents Cannot Work, Not Eligible for Assistance with Child Care	1
Capitated Funding Helps with Reliability	1
Mental Health System is Money-Driven - Leaves People Out	1
Medicaid and Managed Care	17
Private Pay Kids are Difficult to Get Services For - Dependent on Managed Care	9
Must be Given a Diagnosis to Get Funding - May Not Always be Appropriate	5
Ability to Pay Funding, Not Limited by Medicaid	3
Not Enough Providers Accepting Coupons	2
No Services for Undocumented Kids	2
Medicaid Integration Project Working Well	1
General Program Funding	13
Simply Not Enough Funding to Serve All Who Need It	5
Need More Stability of Funding	4
Not Enough Funding for Diagnostics and Testing	2
Personnel Costs Make it Difficult to Provide Adequate Funding Within the Current Funding Structure	1
Peer-to-Peer Supports Should be Available Across the Board Regardless of Funding Source	1
Mental Health Staff Pay	5
Mental Health Staff Poorly Paid/Should Be Paid More Appropriately	5
Availability of Services/Access to Care	73
Access to Care Difficult for Non-Medicaid or Private Pay	19
Need More Access Points	12
If you are Eligible there is an Array of Services that are High Quality and Work Well	10
Takes Too Long to get into Services/To Get Access to the System	9
Schools Serve as Central Locations for Services	3
Lack of Programs Geared for Children, Youth and Families	3
Each of Frograms Scarca for Smilaren, Fourth and Families	
Better Access to Psychiatrists Needed	3
	3
Better Access to Psychiatrists Needed	
Better Access to Psychiatrists Needed Medicaid Limits Availability and Quality of Service	3
Better Access to Psychiatrists Needed Medicaid Limits Availability and Quality of Service Private Pay Services are Not Available - Must Have Medicaid	3 2

Should Not be Such a Gap Between Child and Adult Services	1
No Profound Delays in Accessing Services	1
Dependable Safety Net of Primary Care, Hospital Care, other Services to Catch People at Many Levels	1
Most seriously needy Children are Receiving Services	1
Continuity of Care/Integration	60
Integration and Collaboration	52
Counties Not Working Together - Could Use A Central Agency	16
Not Enough Partnering Between Mental Health and Schools	9
Lack of Encouragement for Service Provider Partnerships	7
Consideration for Co-Occurring Disorders	3
Better Continuity Between All Mental Health Services	3
Good Collaboration Between Agencies	3
Better Integration of Mental Health and Courts	2
Between Mental Health Agencies and Schools	2
Access to Care Standard Are Too Reactive	2
In-House Treatment Providers Instead of Contracting Out	2
Duplicative Efforts Between Multiple Bureaucratic Agencies	1
Two Tiered System (crisis intervention followed by a more developed system after crisis)	1
MIS System to Allow Streamlining of Transfers and Referrals	1
Mental Health and Primary Care	8
Integration and Communication Between Primary Care and Mental Health	6
Train Primary Care Physicians/First Responders about Mental Health	4
RN's Need Training in Childhood Issues	2
Need Medical Coverage that Does Not Include a Spend Down	2
Behavioral Health Consultants in Primary Care	2
Education for Identification of Mental Health Disorders by Primary Care Physicians	1
Hard for Primary Care Physicians to Bill for Mental Health	1
Training and Education	50
Public Education Around Mental Health Issues/Destigmatization	15
Mental Health Professionals Need Better Training in Children's Issues	11
Teachers Not Well Equipped to Deal with Behavior Problems	10

Parent Education	4
Parenting Classes	3
Counselors Not Trained Well in Family Models and Don't do their Background Work	2
Crisis Intervention Training for Police Officers	2
Need More Social Skills Training Programs	2
DSHS should Train Mental Health Professionals in Children's Issues	1
Foster Care	39
Other Issues Related to Foster Care	22
Foster Kids - Decrease Discontinuity Between Placements	2
Mental Health Needs for Foster Kids Not Adequately Being Met	2
Child Can Get Services With Coupons but Parents Don't Qualify and Can't Get Help	2
Too Much Cost Associated with Litigation and Remedial Programs - Early Intervention Would Curb This	1
Respite Care Allows Work With Whole family Not Just the child	1
Increased Accountability for Foster Parents	1
Amazing Parents in the Foster Care System	1
Adults Fighting Over the Children is Detrimental	1
Parents Need to Be Advocates of Their Children	1
Moved From Home to Home	1
Changes Without Warning	1
Find Out More About the Child	1
Child Needs to be More in Control of Their Life and Situation/Take Away All Their Power	1
Need More Follow-Up in the Home	1
Do a Good Job With Reunification and Permanency Planning	1
Lack of Team Building for Multisystem Children	1
Mandated to Provide Mental Health Services But No Supports to Do So	1
Better Supports to Keep Kids in Foster Homes and Out of Hospitals/Jail	1
Screening of Homes and Parents in Foster Care	1
Access	11
Need More Foster Homes	4
Children in Foster Care Have Access to Trained Child Mental Health Providers	2
Too Long for Foster Care Services to Activate	2

Excellent Access for Services for Children in Foster Care	1
Access for Those in Foster Care is Very Difficult	1
Foster Care Infants and Toddlers have Access to Trained Infant Mental Health Service Providers	1
Training	6
Inadequate Training for Foster Parents	4
Not Enough Practitioners Trained in the Unique Needs of Foster Kids	1
Foster Care Classes in High School Curriculum	1
Family Support	32
Need More Services Available to Support Family Members of Mentally III Child	16
More Respite Services (current system requires a child to be in crisis before services and supports are activated)	6
Family Should Be the Consumer Not Just the Child	5
Greater Awareness of Community Services for Families	2
Early Childhood Programs Integrate Family Support/Education	2
Network of Family Advocates is Strong	1
Administrative Concerns	24
Too Much Administrative Burden on clinicians and Paperwork for Clients	10
Limited Time/High Case Loads for Psychiatrists, Counselors, and School Counselors	6
High Staff Turnover Rates	6
Need to Decentralize	2
Transitions	21
Transitions OUT OF Services	12
Transitions OUT OF Services Difficulty With Transitions Out of Mental Health Placements - More Work Preparing Family for Re-Integration	
Difficulty With Transitions Out of Mental Health Placements - More Work Preparing Family for Re-Integration Parents Need to Be More Aware of Treatment - Better Partnership with Treatment Providers	12
Difficulty With Transitions Out of Mental Health Placements - More Work Preparing Family for Re-Integration	12 4
Difficulty With Transitions Out of Mental Health Placements - More Work Preparing Family for Re-Integration Parents Need to Be More Aware of Treatment - Better Partnership with Treatment Providers Have Done a Good Job Creating Family-Friendly Partnerships and Liaisons with Programs and	12 4 3
Difficulty With Transitions Out of Mental Health Placements - More Work Preparing Family for Re-Integration Parents Need to Be More Aware of Treatment - Better Partnership with Treatment Providers Have Done a Good Job Creating Family-Friendly Partnerships and Liaisons with Programs and Agencies	12 4 3 2
Difficulty With Transitions Out of Mental Health Placements - More Work Preparing Family for Re-Integration Parents Need to Be More Aware of Treatment - Better Partnership with Treatment Providers Have Done a Good Job Creating Family-Friendly Partnerships and Liaisons with Programs and Agencies Youth Should Not "Age Out" of System if Still Dependent on Parents After Age 18	12 4 3 2 1
Difficulty With Transitions Out of Mental Health Placements - More Work Preparing Family for Re-Integration Parents Need to Be More Aware of Treatment - Better Partnership with Treatment Providers Have Done a Good Job Creating Family-Friendly Partnerships and Liaisons with Programs and Agencies Youth Should Not "Age Out" of System if Still Dependent on Parents After Age 18 Full Integration of Children with Mental Illness Into the Community	12 4 3 2 1 1
Difficulty With Transitions Out of Mental Health Placements - More Work Preparing Family for Re-Integration Parents Need to Be More Aware of Treatment - Better Partnership with Treatment Providers Have Done a Good Job Creating Family-Friendly Partnerships and Liaisons with Programs and Agencies Youth Should Not "Age Out" of System if Still Dependent on Parents After Age 18 Full Integration of Children with Mental Illness Into the Community Better Funding and Support for Transitional Services	12 4 3 2 1 1

Transitions BETWEEN Services	4
Services for Kids Between EBD Classrooms and General Ed Are Needed	2
Different WAC Reporting Requirements Create Problems for Blending Programs	1
Need for Short-Term Eval, Triage, Stabilization Services Between Outpatient and Inpatient	1
Early Intervention	18
Early Intervention Approach and Focus of Programs	12
System Now is "Crisis-Driven"	6

WASHINGTON STATE MENTAL HEALTH TRANSFORMATION GRANT Public Testimony Summary and Analysis CHILDREN, YOUTH AND FAMILIES SUBCOMMITTEE

Selected Representative Quotes

Availability of Services

The thing that I think would be available with the transformed system would be the accessibility to all, including parents, for wraparound services for their kids, real wraparound services. You know, we talked about kind of wraparound services, but nobody wants to tell anybody anything. --March 1st CYF transcript

Types of services/service characteristics

I work with a dear friend who has shared with me his experience when his daughter was in high school a few years back and she suddenly disappeared. He had no idea where she was. It took him eight days. And he thought he had a fairly happy home life and so forth. It took him eight days to find out that she had been secreted away to the Cocoon House, and she ended up back home again. He still doesn't know if she had an abortion or whatever, but she ended up back home again. Somebody believed her when she said that she got mad at dad and apparently said that, "I'm homeless." And somebody took her off to a counselor and the counselor took her off to the Cocoon House and for eight days he didn't have any idea where his daughter was. And she did ultimately come back home, but what a travesty.

--March 1st CYF transcript

Accessibility, Funding, Types of services/service characteristics

There are not enough providers in our area that accept medical coupons. The services that are provided by our case managers are not always therapy, which a lot of the clients need. If there's limited resources for the youth it seems that the amount of time that they're given for the services as well is cut. There is no longer a multicultural program for youth in our community, which needs to be addressed. There's not enough ethically diverse staff in the area, not enough housing for youth for transitioning into adults, and the criteria that them lose their housing if they're accessing the housing with mental health reasons and then they lose the housing because of this reason without providing another housing opportunity puts them into the street where they become more endangered, and, also, youth are not receiving enough mental health assistance in the juvenile criminal system as well.

--March 1st CYF transcript

Funding

If you don't have private pay insurance, if you don't have transportation, you are unable to access any mental health services in Darrington. You don't have any options about whether or not you get along with your therapist or whoever you see if you don't have private pay insurance.

--March 1st CYF transcript

Family support/Effectiveness

Also, kind of early intervention would be better awareness for the community so when the kids are born with these issues, they're not blaming one another and trying to, you know, ignore and avoid the issue so negative habits start to really grow and become a way they deal with things. --March 1st CYF transcript

Family support

More Respite for the parents who are dealing with the mental health service -- I mean, with a kid who has mental health issues so that they don't just lose it one night with their kid because they don't know what to do.

--March 1st CYF transcript

Transitions

My daughter spent a week in the hospital to get stabilized and medicated. When she came out of the hospital, Fairfax Hospital with their services there could not even set me up with a child psychiatrist and counselor up here in Snohomish County, absolutely unbelievable. With money, with education, with two very determined and loving parents who would do anything for their child, like most of us would, and are capable, we could not find care for my daughter. They sent me off with a psychiatrist's name who didn't even treat children.

--March 1st CYF transcript

Availability of services/Training

There is terrible access up here in the city of Everett for children's mental health issues and because of that, it extends to the schools. We educated our school counselor on what bipolar disorder even was and our principal and the people in the schools who are supposed to be helping with mental health services. They were lovely people. We are so fortunate. The school district is a wonderful place to be, but they were so uninformed it was unbelievable, even to the point when my daughter just simply needing a place to sleep -- pretty much every day about 1:00 o'clock she could no longer stay awake from the high anxiety, from the medications, whatever, our school could not even accommodate her needing to take a nap.

--March 1st CYF transcript

Transitions

There's nothing transitional between an EBD class and a resource special ed room, and it's very difficult for children when they're leaving an EBD class and going into the general population again because the best that we can do for them is to send them to the resource room for extra support and to modify their assignments like crazy..... So, one of the things that I think would be fabulous, if you can find a way to do it, would be to give these EBD kids some kind of inbetween point as they're leaving EBD and going into the general population.

--March 1st CYF transcript

Family Support

The other thing that I would really like to see is something that I can sum up in three words, Respite, Respite, Respite. I can afford a babysitter, but I can't find one who wants to work with a psychotic child. We have no family here. That means we don't go anywhere. Parents of kids with special needs are desperate for Respite, and there's very little out there for them.

Funding/Availability of services

So, what money could be saved to help public funding was if we had effective community-based treatment centers. There was not an entity for us to put Brennan in; and what he needed and what he had, in effect, was a day treatment program. That doesn't exist. [woman whose husband shot and killed Brennan [grandson] and himself in front of the police station] --March 1st CYF transcript

Outcomes

We want outcomes identified in real world terms. We want Johnny to be able to go to the playground, go down the slide – instead of some physical therapist terms -- or, you know, being able to sit supine, you know, and that sort of thing. So, we're really moving our system toward becoming the family friendly, real life, real every day activities or learning experiences. --March 1st CYF transcript

Family Support

More support groups of all kinds both for families and friends and suffers of mental illnesses themselves need to be established. This takes a realization on the part of the public that it takes volunteers to make support groups as well as mental health professionals themselves that are volunteering pro bono or are supported by funding of some sort to help make these groups effective. We cannot do it ourselves. We would like to, but we can't.

--March 1st CYF transcript

Types of services/service characteristics

And I think that as we think in terms of transforming the system, we really need to think in terms of implementing evidence-based practices by using a concept that comes right out of the system of character of being very grounded in families and families' perceptions of things and culture and the individual -- the individual communities within our state that have a very, very different perception sometimes about how they want their kids treated and how they want to be dealt with within the system. So I think that's a piece that's not yet perfected, and we've got a lot of work to do on that.

--February 6th CYF transcript

Transitions

So one thing that I think is not working is that there's a lot of trainings being offered to foster families. Oftentimes -- my daughter is at CSTC, and the big thing she says isn't working is the transition. She has also been at Martin Center, which is a Bellingham inpatient psychiatric care that is long term. And her need was that when she left Marten Center, she was immediately home and had to do the transition. And the whole healing of children is a family healing. Not that we did something wrong, not to blame, but the whole family has to learn a different lifestyle of living or else everything that our kids go and get from these inpatient places is foreign to us when they return home.

--February 6th CYF transcript

Transitions

Another thing is when they get treatment and you aren't able to communicate with the therapist because of privacy, being able to have family professional partnerships that allow parents to know the treatment plans since we live with them the other six days of the week, to build that partnership is going to help these children, and that's not happening.

--February 6th CYF transcript

Family Support

And speaking of that, the other outcome I'd like to see is some support for siblings. I cannot tell you the hell my son, who's now 15, has gone through because of his sister's mental illness. I took him to NAMI because -- just for his own healing and so that he can understand more. And that was good. But there's no support system for him out there. There aren't adolescent groups that I can take him to and he can hear from other siblings of mentally ill kids or even behavior disordered kids. I mean, it's all of the siblings of these kids. And there are probably more siblings than there are the child consumers. And they're all suffering. And we're going see just like with kids of alcoholic parents, those kids are going to still have the effects when they're grown ups. And so we're talking about lifelong problems for these kids because their needs are being neglected.

--February 6th CYF transcript

Funding

This is why it's very important to me where the rubber meets the road that the money does need to follow the kids because it just doesn't happen.

--February 6th CYF transcript

Foster Care

The other thing is a different way for us to approach the serving of foster kids. The foster care system is not part of the mental health system, but we in the mental health system serve many, many foster kids, and there's a great difficultly in doing that for a number of different reasons. Sometimes it can be that the mental health provider is really seen primarily as a tool to be used by the DSHS case manager, and once we've provided our function, then we are thrown away. --February 6th CYF transcript

WASHINGTON STATE MENTAL HEALTH TRANSFORMATION GRANT Public Testimony Summary and Analysis

YOUTH IN TRANSITION SUBCOMMITTEE April 3, 2006

Introduction

The current report represents an analysis of the content of public testimony related to the Youth in Transition Subcommittee of the Washington State Mental Health Transformation (MHT) effort. The report provides a summary of statements presented during the public testimony periods of Subcommittee meetings, as well as additional information received by the state MHT team determined by the research team to be relevant to this Subcommittee. These additional pieces of information include public comments received via email, fax, web survey, or handwritten statements, and also relevant feedback submitted from entire agencies or organizations, some of which engaged in their own group processes before compiling and submitting their input.

The analysis presented here also includes information received from other sources during the course of the MHT planning process, such as Regional Support Network (RSN) reports of priorities and transcripts from statewide MHT "Listening Sessions." Finally, statements provided in other Subcommittees' public hearings that were determined to be relevant to the Youth in Transition Subcommittee were included in this analysis.

Method

Across the many sources of data listed above, information received and analyzed typically were responses to a consistent set of 4 open-ended questions posed to individuals statewide:

- 9. Within Washington State, and for all mental health services, public or private, what is working well when addressing the needs of mental health consumers?
- 10. Within Washington State, and for all mental health services, public or private, what is NOT working, creates barriers or fails to provide quality service and support when addressing the needs of mental health consumers?
- 11. What would a "transformed" mental health system look like?
- 12. What outcomes would indicate that the changes in the mental health service systems are creating improved results for consumers?

Data were received from the state MHT team in the form of transcripts from Subcommittee meetings (created by a legal transcription service), reports from RSNs, emails and web surveys forwarded from public constituents, and Adobe Acrobat "PDF" files of handwritten testimony. A team of PhD-level researchers then conducted qualitative analysis of these raw data using a technique described by Marshall & Rossman (1989). First, unique statements were isolated and summarized from all individual testimonials received. Next, categories were created and all statements sorted by these categories. Third, new categories were created for statements that did not fit the initial categories. Finally, small categories were sorted into primary categories.

Questions about this report can be directed to:

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To increase ease of use and interpretation, a single analysis of all statements was conducted. The information presented here combines responses to all four questions into a single summary of all testimony received. The purpose of the report is to provide Subcommittee members and others working on the MHT project a record of all the public feedback received that is relevant to this Subcommittee, organized in a way that allows for observation of the relative amount of testimony provided within each topic area, and discussion of priorities for action.

The current report

The current report consists of three main sections.

- The first section presents an **overview** of the analysis, including data sources and total number of unique statements coded. This section also includes a brief narrative summary of the findings.
- The second section presents the **results of qualitative analysis in detail**. This Table presents unique themes expressed in public testimony, organized by primary and secondary categories. For each unique theme, the number of statements that were found in the data related to that theme is presented. It is hoped that this Table will be a useful reference for the Subcommittee as it reviews the priorities presented by the public for action.
- The third section presents a number of **direct statements and quotes** from the meeting transcripts and other information received, grouped by major themes.

Acknowledgments

Data analysis for the Mental Health Transformation Public Testimony Summary and Analysis Reports was conducted by:

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Sabina Low Sadberry, Ph.D., University of Washington Evans School of Public Affairs

WASHINGTON STATE MENTAL HEALTH TRANSFORMATION GRANT Public Testimony Summary and Analysis YOUTH IN TRANSITION SUBCOMMITTEE

Data sources:

- 10. Transcript of subcommittee hearing #1: Feb. 22nd, 2006 (Burien, WA)
- 11. Transcript of subcommittee hearing #2: February 27th, 2006 (Vancouver, WA)
- 12. Transcript of subcommittee hearing #3: March 9th, 2006 (Spokane, WA)
- 13. Feedback submitted from RSNs statewide
- 14. Additional written documents from individuals, agencies, and organizations statewide

Total Statements coded = 112

Summary of findings

Public testimony relevant to the Youth in Transition Subcommittee consisted of 112 unique statements coded from individuals who gave testimony at public hearings, as well as additional documents submitted by individuals, agencies, and organizations. These 112 statements were sorted into 11 main categories or themes. The category into which the most statements (24 statements) were coded was commentary about the quality of services and standards for services provided, followed by a second category (16 statements) related to the availability of services and service capacity. Public education and availability of information (13 statements), access to care and related age of consent issues (12 statements), description of services that are promising or working well (11 statements), and financing issues (10 statements) also were major themes. Other themes included housing, collaboration with schools, need for services to be specific to 18-21 year olds, and screening and assessment issues. These themes are summarized below.

What were the major themes?

- Emerging adults have their own unique needs, and the current system does not seem adequate for those who are no longer children but qualitatively different from middle-age adults; they feel "suspended" between systems. For example, where do 21-24 year-olds go for acute crisis care or acute eating disorder treatment?
- Mental health must be addressed in order for youth to successfully transition to adulthood.
- The shift in financial and social supports makes transitioning adults particularly vulnerable to "falling through the cracks."
- There is a need for continuity and collaboration between agencies/services and comprehensive, multi-disciplinary approaches to treatment.
- The system does not adequately identify, treat and provide ongoing supports for those with co-occurring disorders.
- Families and youth feel confused by system and need education and advocacy in order to maximize quality of care.
- Standards of access to care seem overly stringent; need flexibility in options for those who are less "severe."

What is working well?

- Community-based youth support programs (Youth House, Connections, Clubhouses)
- Parent support/education programs (YES, Pebbles in Pond)
- Holistic, comprehensive services in housing communities (e.g., New Futures, Wonderwood)
- Vocational support/training programs (e.g., Worksource, Ticket to Work, Project Dream)
- Grass-roots volunteer groups
- Wraparound programs

What is not working well?

State support is not consistent

• Need for consistency across state in provision and quality control of services and screening (e.g., inconsistent availability of wraparound, inpatient beds, screening).

There are many financial barriers, including stable housing

- Transitioning youth, especially vulnerable youth, need stable housing.
- Transitioning youth face significant obstacles and discontinuity in benefits: eg, SSI re-determination age, Medicaid cut-off, loss of parents' insurance coverage.

Need for psychoeducation and to reduce stigma

- Need for education around benefits, service options, mental disorders.
- The public needs more education about mental health issues, toward a reduction in stigma against these individuals.

Service Capacity

- Need for increased inpatient beds
- Need for increased triage services from crisis/acute care and/or involvement in juvenile system
- Need for increased services for those with co-morbid disorders

Service Quality is inconsistent and must be addressed

- Need for comprehensive, multi-disciplinary wraparound services
- Need for continuous quality control
- Need for family-centered, individualized care, and the financial supports to allow families to be part of care (e.g., travel money).
- Systematize standards of access to care statewide

Need additional support for vulnerable youth in foster system, juvenile court system

- Need for transitional services, vocational supports, housing
- Need for early entry-screening across state

Point of entry barriers

- Families see age of consent as barrier rather than protection for youth
- Families feel frustrated in getting children involuntarily committed
- Families feel like they have not options if youth are not "severe."

A full summary of all themes and statements within each theme is presented in the Table on the following pages.

Table 1.
Results of qualitative analysis of public testimony for the Youth in Transition Subcommittee (N=112 statements total).

Themes	Number of statements
Standards/quality of care	24
Family-centered/individualized care	6
Coordinated System of care / Wraparound	5
Cross-system collaboration	4
Continuity in care after age 18	3
Integrate evidence-based treatment into standards	2
Need Medicaid to support travel for long-distance care	1
Need for more outreach	1
More direct service could be provided if RSN system were replaced (lose money to inefficiency/bureaucracy)	1
Need for continuous quality improvement	1
Service Capacity	16
Services needed	9
Need more services outside King County	4
More short-term, crisis, stabilization services	3
Need more inpatient beds	1
Services that treat crhonic physical and mental health problems	1
Transitional services (e.g., from crisis care, acute care) or for vulnerable populations	7
More transitional/triage services out of mental health and education system	5
Need transitional services for youth in foster care and juvenile system	2
Need for more Psychoeducation and help navigating the system	13
Stigma/Public education	6
Need for Internet resources, state-on line forum/information warehouse	4
Need benefits counselors to help navigate benefits system, determination, application process	1
Lack of education for 'dual eligibles' (i.e., Medicaid/SSDI) and ability to choose drug plans	1
Medicare Part D Confusing and cumbersome	1
Access to care standards and age of consent barriers	12
age of consent at 13 seen as barrier	4
Continuity in services for foster youth "aging out" and youth in juvenile justice system	3
access to care standards too stringent	2
make autism Medicaid reimbursed	2

Themes	Number of statements
age of consent misinterpreted	1
Some Programs and Efforts are Working Well	11
Parent Support	3
YES Parent Support program working well	1
Pebbles in Pond Parent Group	1
Local support groups	1
Vocational Training/Support Programs	3
Project Dream vocational training	1
Vocational Programs (e.g., Worksource, Ticket to Work, Career Path Services)	1
SEAR (Spokane)	1
Youth Support Programs (Options, Connections, Youth Source)	4
Clubhouses	2
Programs for Transitioning youth (e.g., Mockingbird, Treehouse, Common Voice)	1
Safe Laws, Youth in Action	1
Comprehensive, holistic community-based projects are beneficial (Daybreak, New Futures)	1
Financial Barriers	10
Increase flexible spending, money for wraparound and cross-service use	2
Medicaid coverage for psychotropic medications limited	1
Medicaid benefits for mental health visits vs. pharmaceuticals sometimes inconsistent	1
Medicaid Cutoff at age 18	1
SSI Redetermination Age: need other supports in place if youth lose SSI at age 18	1
DDD cutoff for foster youth at age 18	1
SSI difficult to obtain and maintain after 18 due to bureaucracy	1
Increased funding for co-occurring disorders Medicaid food coupons insufficient	1 1
Housing supports	6
Transitional housing limited (esp in rural communities	4
Employer financial supports for housing needed	1
Housing stability important	1
Screening and Treatment for Co-morbid SU/MH disorders limited	6
Need for more treatment services for this population	2
Need for early identification co-morbid disorders	2
Lack of transitional services for CD youth in transition (age 18)	1
No consistent screening for co-morbidity in juvenile justice system across state	1

Themes	Number of statements
Collaboration with Schools/School supports	5
Schools need to increase vocatinal training for SED students	1
Improved IEP	1
Enhanced youth say in IEP	1
More school-agency collaborations	1
Youth want more input on IEP plans	1
Screening	5
No screening in diversion across state	1
Need screening in the educational system	1
after age 18, no screening in MH courts	1
Mental health/drug courts limited to King County	1
Inconsistent screening in juvenile courts	1
Services need to be specific to 18-21 year-olds	4
many adult services/facilities not appropriate for young adults	2
Transportation, flexible scheduling for young adults who are working and going to school	1
no appropriate facilities for young adults with co-morbid disorders (treatment facilities ignore unique needs of this population)	1

WASHINGTON STATE MENTAL HEALTH TRANSFORMATION GRANT Public Testimony Summary and Analysis YOUTH IN TRANSITION SUBCOMMITTEE

Selected Representative Quotes

Youth ill-prepared to assume demands of adulthood at age 18

"So you're a young person who's been told they have no future from age 7. They have IEP's. They have the label. They're going through school. They've been told there's something radically wrong with you, so we're going to put you over here in the radically wrong room and – you transition into the adult System of Care where they're expected to make all of their own choices. "So what doesn't work is when you take young people who never had a opportunity to speak for themselves, who've never known they could speak for themselves and tell them they can speak for themselves. My son needed to have the dignity of his own process."

"When kids in the system turn 18 and enter the adult system, they have no reason to have hope and to have the skills to be able to navigate the system. And they don't have their mom to advocate on their behalf any more."

"So I've seen it firsthand what happens when someone's going to transition from the alcohol and drug, COD, program that we have at Native Projects when they transition into the adult system. There is no absolute welcome. If they don't have Medicaid, they may as well forget about getting their medications. There's supposed to be this magical cutoff date when someone turns 18 that all of a sudden they're adults and they should know how to do this, and I believe that we abandon them. We force them into the streets, and we say, "Go to Spokane Mental Health," here. I'm sure it's somewhere else there, but well meaning, you know, put these 18-year-olds in with people who are 50, 60 years old, maybe have been in the mental health system forrever. So you're looking at putting them into a system where they're all treated the same. In actuality, they're late adolescents and need to be treated as such.

Parent support

"Parents are exhausted and what doesn't work—is that we do not have resources for parents because exhaustion is not a criteria for access, so we don't have resources for families to help them process what's happening in their family. And we don't have help for families to help them understand how much of this is part of normal adolescent transition into young adulthood and how of this is disability."

Stigma

"What we need is to be able to get families the help they need without having to label themselves and their children as mentally ill. If we could provide support for families...outside the mental health system, maybe they wouldn't worry about the stigma."

Unmet Need

Director of Janus Youth Programs. "We have 3 shelters here in Washington, and what I'd like to say is that when I started 10 ears ago, the type of kids we were seeing were a whole lot different than what we're seeing today. The kids we're seeing today have a lot of mental health issues,

some have a lot of dual diagnosis, we have a lot of suicidal kids, a lot of BRS type kids. And although the type of kids have changes, the services and funding to provide these kids with what they need has not."

We provide crisis shelter, and we want to work with these kids, but we need help from services in the community to be able to provide trackers or somebody who can come and speak to these kids in person, not on the phone. They need to see somebody face-to-face."

Inconsistent services by funding and geographic location

"That brings up that -- you know, it's actually, if you're a very impaired kid, it's better to be on Medicaid than private insurance. There should be some way to partner with the private insurance to fill in the gaps for those kids, as well as the non Medicaid population. So we're lucky we have the IST in King County, but that only serves x-number of kids. There's wait lists."

Mental Health/Physical Health co-morbidity

"And the other thing, it's just a broad concept that I keep thinking about, is that we really need to think about mental health more in the context of physical health. You know, we've still got that big division between mental health, physical health, and there isn't that division. The brain is part of the body. And I feel like sometimes these kids don't get a thorough physical evaluation. That's all I have to say."

Need for continuity in state-financial supports

I just had one comment. My kids get to stay on my private insurance until they're 22. Why can't we let kids on a medical coupon be considered a kid until they're 21 so they can get access to Medicaid in that 18 to 21 years old. That's when we see them really fall off.

Family-centered care not financed by Medicaid

The other thing that hasn't really been brought up that is of concern to me is when you have a child in CYT over in treatment, which is, of course, over there on the other side, and when you're over here, or you're in Republic, Washington or Kettle Falls, and you're supposed to be having visitation, and you're on coupons and on Medicaid, how can you afford to be traveling back and forth be seeing your child, to be integrated in your child's care and treatment?

WASHINGTON STATE MENTAL HEALTH TRANSFORMATION GRANT Public Testimony Summary and Analysis

OLDER ADULT CONSUMERS SUBCOMMITTEE April 4, 2006

Introduction

The current report represents an analysis of the content of public testimony related to the Older Adult Consumers Subcommittee of the Washington State Mental Health Transformation (MHT) effort. The report provides a summary of statements presented during the public testimony periods of Subcommittee meetings, as well as additional information received by the state MHT team determined by the research team to be relevant to this Subcommittee. These additional pieces of information include public comments received via email, fax, web survey, or handwritten statements, and also relevant feedback submitted from entire agencies or organizations, some of which engaged in their own group processes before compiling and submitting their input.

The analysis presented here also includes information received from other sources during the course of the MHT planning process, such as Regional Support Network (RSN) reports of priorities and transcripts from statewide MHT "Listening Sessions." Finally, statements provided in other Subcommittees' public hearings that were determined to be relevant to the Older Adults Subcommittee were included in this analysis.

Method

Across the many sources of data listed above, information received and analyzed typically were responses to a consistent set of 4 open-ended questions posed to individuals statewide:

- 13. Within Washington State, and for all mental health services, public or private, what is working well when addressing the needs of mental health consumers?
- 14. Within Washington State, and for all mental health services, public or private, what is NOT working, creates barriers or fails to provide quality service and support when addressing the needs of mental health consumers?
- 15. What would a "transformed" mental health system look like?
- 16. What outcomes would indicate that the changes in the mental health service systems are creating improved results for consumers?

Data were received from the state MHT team in the form of transcripts from Subcommittee meetings (created by a legal transcription service), reports from RSNs, emails and web surveys forwarded from public constituents, and Adobe Acrobat "PDF" files of handwritten testimony. A team of PhD-level researchers then conducted qualitative analysis of these raw data using a technique described by Marshall & Rossman (1989). First, unique statements were isolated and summarized from all individual testimonials received. Next, categories were created and all statements sorted by these categories. Third, new categories were created for statements that did not fit the initial categories. Finally, small categories were sorted into primary categories.

Questions about this report can be directed to:

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To increase ease of use and interpretation, a single analysis of all statements was conducted. However, this report also includes a Table with responses broken out by all four questions. The purpose of the report is to provide Subcommittee members and others working on the MHT project a record of all the public feedback received that is relevant to this Subcommittee, organized in a way that allows for observation of the relative amount of testimony provided within each topic area, and discussion of priorities for action.

The current report

The current report consists of three main sections.

- The first section presents an **overview** of the analysis, including data sources and total number of unique statements coded. This section also includes a brief narrative summary of the findings.
- The second section presents the **results of qualitative analysis in detail**. This Table presents unique themes expressed in public testimony for each of the 4 Mental Health Transformation questions, organized by primary and secondary categories. For each unique theme, the number of statements that were found in the data related to that theme is presented. It is hoped that this Table will be a useful reference for the Subcommittee as it reviews the priorities presented by the public for action.
- The third section presents a selection of **direct statements and quotes** from the meeting transcripts and other information received, grouped by major themes.

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WASHINGTON STATE MENTAL HEALTH TRANSFORMATION GRANT Public Testimony Summary and Analysis OLDER ADULTS SUBCOMMITTEE

Data sources:

- 15. Transcript of subcommittee hearing #1: February 16th, 2006 (Seattle)
- 16. Transcript of subcommittee hearing #2: March 2nd, 2006 (Spokane)
- 17. Relevant statements from Adult Consumers Subcommittee and Children, Youth, and Families Subcommittee meetings
- 18.RSN responses to the 4 Transformation Questions that specifically address this Subcommittee's population
- 19. Additional written submissions from individuals, agencies, and organizations statewide

Total Statements coded = 286

Summary of findings

Public testimony relevant to the Older Adults Subcommittee consisted of 286 unique statements coded from 30 individuals who gave testimony at public hearings (or written submissions) as well as additional documents submitted from individuals, RSNs, and other agencies and organizations. Fifty-one statements were coded from responses to the question "What is working well," 95 statements were coded from responses to the question "What is not working well," 119 statements were related to the question about what a transformed system will look like, and 21 comments were coded regarding proposed outcomes of a transformed mental health system.

A brief summary of the results across the four questions is provided below:

- A main point of testimony was found to be that **Older Adults Do Not Seek Treatment** and they also often **Refuse Treatment** when it is offered or even mandated. Outreach and case finding practices were thus mentioned as being useful and needed. The reduction of mental health stigma is related to this issue and is seen as an area of emphasis for a transformed system.
- Residential Services and Adult Family Homes were noted as working well and also as something that needs to be added since there are inadequate resources in these areas.
- Access to Care is seen as being discriminatory to older adults. Some common reasons: treatment and practices and intake and outreach procedures are not specific to older populations and do not take into account their unique needs.
- **Under-Funding** of services for this (and other) populations was noted consistently in testimony.
- Lack of Flexibility of funding and funding options was also noted as being a barrier to receiving quality treatment. Non-Medicaid Funding options are very scarce. Those without Medicaid are often excluded or alienated from treatment.

- Lack of Integration between services and programs: An increase of integration would be helpful. The most common issues: utilizing multiple services without communication of any sort between the two, as well as a lack of involvement with the medical community, in which many mentally ill older adults are involved.
- **Treatment Providers** are viewed as not being competent to serve the needs of older adults and not having enough training about this population. Understaffing across the board was also noted.
- One suggestion for a transformed system that arose often was the need for In-Home Adult Care and Treatment. Transportation needs are also tied to this issue. Older adults often do not have transportation to get to services and supports. Providers that would be able to go to their homes for appointment would make access easier, increase the level of comfort for the patient, and would eliminate the need for transportation services to get these people to their treatment providers.
- Staff Wages are viewed as being unfairly low. This causes turnover which upsets older adults who are served by new care professionals all the time. Another issue related to turnover is case loads. Case Loads are too high to provide adequate services to the clients and are adding to the turnover rate since staff are overworked.
- A transformed system would also include Well-Trained Staff in the area of geriatrics.
 Staff and treatment professionals are currently seen as not being educated about this population.
- Other issues: too many older adults having to go to emergency room for treatment, which is not good MH treatment and is very costly; older adults are too often incarcerated instead of going to MH professionals; older adults are feeling very ignored in the MH system, despite the high number of mentally ill older adults.

A full summary of all themes and statements for each of the four questions is presented in the Table on the following pages.

Table 1.
Results of qualitative analysis of public testimony for the Older Adults Subcommittee (N=286 statements total).

Themes	N Statements
What is working well?	51
Mental Health Services	41
Type of Programs or Services	19
Residential Services/ Adult Family Homes	7
Case Finding Practices	4
Older Adult ECS Programs	3
Clubhouses (work because they are peer-to-peer)	2
Integrated Services	2
Elderly Support Groups	1
Mental Health Services (Specific Examples)	13
Avondale House	3
Midway Residential Program	2
Gatekeeper Program	2
Hope Options	1
Senior INA	1
Adult Day Health	1
Care Cars	1
COPES	1
Assistant Dogs of Puget Sound	1
Treatment Practices	9
Evidence-Based Treatments	2
Diversion practices away from state hospitals	2
Wraparound Approach	2
Prevention-Based Approaches	1
In-Home Treatments	1
Community MH Services	1

Themes	N Statements
Funding	7
Community Services Grant	2
Treatment Options for Non-Medicaid Eligible	1
AAA Long-Term Care - Senior Citizens Service Act	1
Section 8 Vouchers	1
Treatment Expansion Dollars	1
Combined Sources of Funding	1
Education/Training Programs	3
Geriatric Mental Health Certificate	2
Case Workers with broad knowledge and ability to integrate services	1

Themes	N Statements
What is NOT working well?	95
WMH System Problems (general)	40
Limitations to Care For Older Adults	28
Access to care is Discriminatory against older populations	8
Older Adults don't seek/refuse treatment	8
Medicare Discriminates against mental health needs	3
Medicaid too limiting in what it will cover	3
Consumers don't know what is available or where to go to find out	2
Not enough services/programs specific to older adults	2
Too many unrealistic and conflicting laws	1
RSN's discriminate against the elderly	1
General System Problems	12
Paperwork is Unmanageable (for consumers and providers alike)	4
It takes too long to get in after referral/appointment	3
Service Delivery is Inconsistent	2
Too many ER visits - no other options for immediate treatment	2

Themes	N Statements
Too many mentally ill older adults going into criminal justice system	1
Funding	25
Mental Health system Under-funded Across the Board	8
Lack of flexibility of funds	5
None for non-Medicaid eligible	4
Medications too expensive	3
Staff Wages are Unlivable, unfair	2
Too many Insurance Issues around mental health services	1
No Integration of funding sources	1
Lose Funding b/c Clients end up In Medical Hospitals	1
Not enough funding for Gatekeeping programs	1
Treatment Providers	17
Programs Chronically Understaffed	4
Providers are Under-trained in Older Adult mental health	4
High Employee Turnover Causes Distress to Clients	3
Case Loads Too High	3
Not enough Psychiatrists	2
Providers young and not seen as relatable	1
Treatment Practices	12
Lack of Integration	6
Not enough integration with Medical Care	3
Lack of integration between programs and providers of different agencies	3
Practices (General)	6
Privatization doesn't work	2
ECT Treatments	1
Adults in Nursing Homes don't receive adequate treatment for Mental illness	1
Reduction of treatment hours with clients recently	1
Lack of community resources for older adults	1

Themes	N Statements
What does a transformed system look like?	119
Services Needed	27
More Adult home health care options	8
Housing Options	5
Transportation Resources for elderly	4
Add Programs that Fill gaps	2
Specialty Crisis Services	2
Day programs	2
Soft Interventions	1
Rural Services Increased	1
MH treatment at long-term care facilities	1
SA assessments in elderly group homes and own homes	1
Client-Related	21
Access to Care	11
Easier access to care	7
A place to get information about available programs	3
Medications easier to get and to use	1
General	10
Recognition of dementia as a mental illness covered by insurance/Medicaid	3
Increased Safety for Clients in treatment facilities/trying to get to treatment	3
Family feels empowered and not victimized by the system	2
Involuntary treatment centers available	1
Consumers more active in decision-making	1
Training	17
Provide Adequate Training for Staff (general)	7

Themes	N Statements
Provide training about Geriatric Populations Specifically	8
Patient and Family Rights	2
Funding/ Use of Funds	16
Staff Wages Increased	4
Support for Clubhouses	3
Funding Options For Non-Medicaid	2
MH staff at senior centers/nursing homes regularly	2
Increase funds for community mental health	1
PACT Funds	1
Flexible Sources of Funding	1
Combined Sources of Funding	1
Supplement cost of medications	1
Treatment Focus	12
Evidence-based treatment	3
Age-based	3
Prevention Based/Focused	3
Assertive Community Treatment	1
Cultural Awareness	1
Individualized/Tailored Treatment	1
Additional Services	10
Reduction of stigma	6
Recruitment of Older adults/Outreach	4
Treatment Services/Professionals	9
Things to aid treatment providers	6
Reasonable Case Loads	2
State Computerization Effort - get providers on same system	1
Social service network email directory	1
Greater Support from the State Government	1
Increased Safety for Workers/Staff	1
General	3

Themes	N Statements
Consumer peer counselors	1
Use medical social workers	1
More Caregivers trained in mental health	1
Integration of Services/Agencies in general	7

Themes	N Statements
Outcomes of a transformed system	21
Client-Related	14
Reduction of Hospitalizations for mental health issues alone	4
Reduction of Incarcerations	3
Less older adults at state hospitals	2
Increase independent living rates	2
Increased Client Satisfaction	1
Older Adults get mental health treatments	1
Increase in Client Skills	1
Treatment Provider Factors	5
Reduced Number of Case Loads for Providers	4
Reduced Turnover Rate of MH Staff	1
Treatment Services and Delivery	2
Quality Services	1
Decreased intake times/paperwork	1

WASHINGTON STATE MENTAL HEALTH TRANSFORMATION GRANT Public Testimony Summary and Analysis OLDER ADULTS SUBCOMMITTEE

Selected Representative Quotes

Exemplary Quotes

Limitations to Access to Care

"Crisis services for Older Adults do not meet the needs of older adults—they are unresponsive"

Treatment Providers Under-trained in Older Adult

"Older Adults under-use MH services due to MH services not being geared to the different needs of older adults who are have mental health challenges, e.g.: grief and depression can express themselves differently in older adults."

Access to Care is Discriminatory against Older Populations

"Many issues that older adults experience as mental health needs are not funded through mental health dollars. For example: Grief, Dementia, or personality disorders are not adequately addressed by MH services and they can't get services for these disorders."

Limitations to Access to Care – Access is Discriminatory against Older Populations

"Older Adult Mental Health problems don't look the same to the community and are not necessarily funded by MH—therefore older adults may quietly de-compensate in the community until they've reached a crisis point - then the MH system acts."

Limitations to Access to Care – Access is Discriminatory against Older Populations

"Many ways that older adults manifest mental health problems do not meet the MHD's Access to Care standards, and therefore Aging money often funds the gaps by providing services that actually prevent crises before they reach that standard that would allow MH to serve them."

Transformed System – Services Needed – More Adult Home Health Care Options

"Older Adults would receive mental health services in appropriate settings (that is settings that serve the older adults where they live or can very easily reach)"

Limitations to Access to Care – Medicare Too Limiting

"Restrictions/limits to Medicare coverage for mental health. Medicare provides no long-term mental health coverage. Only short-term crisis services and only by RN's."

Funding/Access to Care/Treatment Options for Older Adults/MH System discriminates Older Adults

"Inadequate funding, access barriers, and limited treatment options are among the many issues preventing the mental health system from meeting the needs of older adults."

Stigma/Older Adults Don't Seek Treatment

"Myths held by older adults, the general population, and service providers that being depressed is a normal part of aging. Many seniors resign themselves to feeling miserable without realizing that help is available. Family members and others that interact with seniors may believe that being old is depressing. Service providers in both mental health and aging may also hold some of these beliefs to varying degrees."

Transportation Needed/In-Home treatments needed/Consumer-Driven Treatment Focus

"Too few mental health services are designed to be brought into the homes of older adults. The stigma surrounding mental health problems can prevent seniors from visiting community mental health centers. Health problems, mobility limitations, and lack of transportation can make it extremely difficult for some seniors to leave their homes. In survey after survey, seniors have expressed a strong preference for remaining in their homes and aging in place. The mental health system needs to respond to this consumer preference as well as its obligation to provide services to homebound seniors."

Lack of Collaboration/Integration of Services/Lack of Communication between Providers

"Mental health providers seemingly operate in an insular fashion, and often do not operate collaboratively with other entities, even when there are shared clients. The barriers are so significant that outside agencies, such as our T XIX Case Management Programs, have had to circumvent these barriers and find alternative methods outside the system to get our clientele's mental health issues treated, such as contracting with a Private Psychiatric ARNP using our own agency funds. Primary physicians are the primary prescribers of psychiatric medications, and admittedly are not experts in this field."

Transportation Needed/In-Home Treatments Needed

"Also, most of our mental health providers DO NOT provide in-home services, which are a major barrier for our home bound disabled and elderly clientele whom have difficulty getting to and from services. This is further complicated by the older generation having difficulty accepting mental health services, even if they have a form of medical transportation that takes them to a facility if is known to provide mental health services."

Access of Care/MH System Discriminates Older Adults

"Who else is not getting services? You know, it's interesting in this system that in Medicare, if you are an older adult and had a callous on your foot and you could go to a podiatrist; but if you lost your significant other of 60 years or just moved out of a house and you had these intense grief issues, you can't get services because it's not a diagnosis. If you have a general depression and someone makes the mistake and calls it depression NOS, you don't get in. So, we -- we -- if you are non-ambulatory, you require someone to come out and see you, you don't get in. If you're physically ill, the chances of getting to be seen by a mental health professional is rare. If you are incontinent, you don't get -- you seldom will get the opportunity to be seen by a mental health professional in a facility and God help you if you need a residential facility or an ENT who – right now in our state, if you become mentally ill and you're an older adult and you're incontinent, you won't even get into an evaluation treatment center because they will proudly announce that they're not equipped to handle that. So, where will they go? And that's also including substance abuse, too, by the way."

WASHINGTON STATE MENTAL HEALTH TRANSFORMATION GRANT Public Testimony Summary and Analysis

HOMELESSNESS SUBCOMMITTEE April 3, 2006

Introduction

The current report represents an analysis of the content of public testimony related to the Homelessness Subcommittee of the Washington State Mental Health Transformation (MHT) effort. The report provides a summary of statements presented during the public testimony periods of Subcommittee meetings, as well as additional information received by the state MHT team determined by the research team to be relevant to this Subcommittee. These additional pieces of information include public comments received via email, fax, web survey, or handwritten statements, and also relevant feedback submitted from entire agencies or organizations, some of which engaged in their own group processes before compiling and submitting their input.

The analysis presented here also includes information received from other sources during the course of the MHT planning process, such as Regional Support Network (RSN) reports of priorities and transcripts from statewide MHT "Listening Sessions." Finally, statements provided in other Subcommittees' public hearings that were determined to be relevant to the Homelessness Subcommittee were included in this analysis.

Method

Across the many sources of data listed above, information received and analyzed typically were responses to a consistent set of 4 open-ended questions posed to individuals statewide:

- 17. Within Washington State, and for all mental health services, public or private, what is working well when addressing the needs of mental health consumers?
- 18. Within Washington State, and for all mental health services, public or private, what is NOT working, creates barriers or fails to provide quality service and support when addressing the needs of mental health consumers?
- 19. What would a "transformed" mental health system look like?
- 20. What outcomes would indicate that the changes in the mental health service systems are creating improved results for consumers?

Data were received from the state MHT team in the form of transcripts from Subcommittee meetings (created by a legal transcription service), reports from RSNs, emails and web surveys forwarded from public constituents, and Adobe Acrobat "PDF" files of handwritten testimony. A team of PhD-level researchers then conducted qualitative analysis of these raw data using a technique described by Marshall & Rossman (1989). First, unique statements were isolated and summarized from all individual testimonials received. Next, categories were created and all statements sorted by these categories. Third, new categories were created for statements that did not fit the initial categories. Finally, small categories were sorted into primary categories.

Questions about this report can be directed to:

Eric J. Bruns, Ph.D., University of Washington Division of Public Behavioral Health and Justice Policy ebruns@u.washington.edu - 146 N. Canal Street, Suite 100, Seattle, WA, 98107 - 206-685-2085

To increase ease of use and interpretation, a single analysis of all statements was conducted. The information presented here combines responses to all four questions into a single summary of all testimony received. The purpose of the report is to provide Subcommittee members and others working on the MHT project a record of all the public feedback received that is relevant to this Subcommittee, organized in a way that allows for observation of the relative amount of testimony provided within each topic area, and discussion of priorities for action.

The current report

The current report consists of three main sections.

- The first section presents an **overview** of the analysis, including data sources and total number of unique statements coded. This section also includes a brief narrative summary of the findings.
- The second section presents the **results of qualitative analysis in detail**. This Table presents unique themes expressed in public testimony, organized by primary and secondary categories. For each unique theme, the number of statements that were found in the data related to that theme is presented. It is hoped that this Table will be a useful reference for the Subcommittee as it reviews the priorities presented by the public for action.
- The third section presents a selection of **direct statements and quotes** from the meeting transcripts and other information received, grouped by major themes.

Acknowledgments

Data analysis for the Mental Health Transformation Public Testimony Summary and Analysis Reports was conducted by:

Suzanne E. Kerns, PhD ABD, Eric J. Bruns, Ph.D., Phoebe Mulligan, and Justin D. Smith, University of Washington Division of Public Behavioral Health and Justice Policy Maria Monroe-DeVita, Behavioral Tech Research, Inc.

Sabina Low Sadberry, Ph.D., University of Washington Evans School of Public Affairs

WASHINGTON STATE MENTAL HEALTH TRANSFORMATION GRANT Public Testimony Summary and Analysis HOMELESSNESS SUBCOMMITTEE

Data sources:

- 20. Transcript of subcommittee hearing #1: February 14th, 2006 (Seattle)
- 21. Transcript of subcommittee hearing #2: February 17th, 2006 (Everett)
- 22. Transcript of subcommittee meeting #3: March 10th, 2006 (Yakima)
- 23. Relevant statements from Co-occurring Disorders Subcommittee and Children, Youth, and Families Subcommittee meetings
- 24. Feedback submitted from RSNs statewide
- 25. Additional written submissions from individuals, agencies, and organizations statewide

Total Statements coded = 187

Summary of findings

Public testimony relevant to the Homelessness Subcommittee consisted of 187 unique statements coded from 76 individuals who gave testimony at public hearings (or written submissions) as well as additional documents submitted from individuals, agencies, and organizations. These 187 statements were sorted into 9 main categories or themes. The category into which the most statements (71) were coded was commentary about existing services or service types, including services that are working well, services that are needed, and issues about cultural competence in service delivery. Continuity and levels of care (24 statements), financing issues (24 statements), consumer empowerment (18), and access to services (15) were also major themes. Additional categories included employment, education and training, and collaboration between systems. Finally, there were seven statements that discussed desired outcomes for homeless individuals with mental health problems. A summary of these results is presented below.

Services that were recommended, other than general use of evidence-based practices, were peer-based services, drop in day centers, community services (as opposed to meeting in an office), and street outreach programs. There should be greater funding available for all of these services, as well as funds for training consumers to participate in peer-based services. More broadly advocated for was an overall **continuity of services** between systems, specifically the criminal justice system. Participants often felt that individuals who were released from jail and/or state hospitals were left with no financial or employment resources, which perpetuates the cycle of homelessness. Participants also voiced a need for the mental health system to be more closely linked with housing and employment resources.

Housing and employment services were specifically focused on, with specific attention paid to the lack of affordable housing, strict time limits which impeded any real progress, and additional services for specialized populations (i.e., youth, Native Americans, families, veterans). Additional feedback was given regarding a lack of housing with no clinical strings attached; a homeless person must already be doing "well" in order to receive services. **Ongoing support** was specifically mentioned, as participants felt as though they were being terminated from services before they were able to function on their own.

Education for police officers and the general public about issues of homelessness, the prevalence of mental illness, and de-stigmatizing information was brought up consistently. People with mental illness, specifically homeless people, need to be treated with dignity and respect. Several people also spoke to the lack of information that they have about services and medications; there needs to be better communication between the service providers and the population that they are seeking to assist.

Respondents reported that the system in general seems to be set up for people to fail. **Lack of funding** for programs, elite requirements for participating, inappropriate expectations being placed on those accessing services, and many hoops to jump through for ineffective services are just several of the issues that deter homeless individuals from accessing the available services. One participant pointed out that homeless individuals with mental illness are often considered too "high risk" to be in a group home or transitional housing; the recommendation was that these resources be more prepared to handle mental health issues, as there is a high prevalence in the homeless community.

Overall there should be no wrong door for **accessing services**. Financial support should be provided not only to programs, but also to the individuals accessing those programs. One idea was that the money should follow the individual, rather than being given to the program. This would assist people in starting out with resources and continuing with ongoing support as they begin to rebuild their lives. There is a great need for housing, both shelters and transitional, as most organizations that provide shelter are currently overwhelmed and under-funded. This is also true for **professionals** in the field, who should invested in by organizations (i.e., paid a better wage, given reasons to stay at an organization) so that the faces of providers do not continue to change so quickly, which has a negative effect on those accessing services.

A full summary of all themes and statements within each theme is presented in the Table on the following pages.

Table 1.
Results of qualitative analysis of public testimony for the Homelessness Subcommittee (N=187 statements total).

Themes	N Statements
Types of Services	71
Recommendations for effective models	40
More shelters and subsidized housing with a shorter wait list	10
Street outreach, such as that provided by the PATH program	7
Halfway houses with access to medication and housing case managers	5
Shelters and subsidized housing should have better capacity to deal with mentally ill individuals	4
Safe Havens day treatment center, which provides basic services	3
The Clubhouse system provides a place to learn skills, find community and services	2
Pay more attention to evidence-based practices	2
Service providers need to focus on long-term aspects of treatment	2
Clinicians should work in the community instead of in their offices	2
Everyone should have access to an advocate to help them navigate the system	2
Assertive Community Treatment (ACT)	1
Services that are needed	26
Resources in rural areas	9
More housing for homeless men	4
Permanent housing for disabled homeless	3
Services for homeless youth	3
Healthcare programs that integrate mental, substance use, and physical health services	2
Services for families	2
Drop in day services	2
Homelessness prevention services to help consumers stay housed	1
Culturally specific services	5
The RSN system should be altered to encompass and specifically represent Native Americans	2
Not enough services for Native Americans	2
The system should address mental health and housing needs of Native Americans	1
Consumer empowerment	18
Consumer run programs, like SHARE, are very helpful and should be continued	6
Provide services that give homeless people a purpose and a goal	5
Commit to involving consumers at all levels of decision making, including policy	3
Some housing exists that does not have clinical strings attached	2
Homeless folks should be able to build their own homes and participate in the process	1
The MH system has been focusing on empowering developmentally disabled people	1
Continuity and levels of care	24
Need more crisis intervention and "in the moment" services	7
Need better continuity of care	5
Better communication of services to the target population	3

Living facilities need to match the type of person they are housing	3
Provide ongoing support	2
People placed in facilities with inappropriate level of care	1
Lower standards on how people can qualify for services	1
Providers able to assess and treat people at whatever level they are at	1
Respite care should be increased	1
Access to services	15
Problems	15
Services are often pulled away from people when they're doing well	4
Clients pushed off onto other professionals because social workers not paid well enough to go the extra mile	2
Caseloads are too high for professionals to be effective	2
Outreach workers blame the individual rather than the system	1
Provide assistance to the person, rather than the program; money follows the person	1
Lots of hoops to jump through for ineffective services or services that take too long	1
Fragmented system creates barriers for the most vulnerable	1
The MH system places inappropriate expectations on people who utilize the benefits.	1
People end up on the street because they are too "high risk" for group homes/housing.	1
Solutions	1
Track outcomes of people who leave services	1
Education	10
Educate police officers on mental health issues	5
More effort to educate the public and end discrimination against homeless people	4
Lack of information about medications	1
Financing issues	24
For individuals	9
Without Medicaid there are no available services	4
Need access to affordable medication	2
Money provided by the state is not enough to live on	1
Insurance does not cover all mental illness equally	1
Difficult to access Medicaid services	1
For providers	1
Pay service providers well so that they will stay in their jobs	1
For programs	14
Sufficient funding for all regions to provide adequate services	10
People should not be kicked out of subsidized housing b/c they run out of money	1
Increased funding for hospital alternative services	1
Funds would be available to train consumers in peer support services	1
Money for new housing developments	1
Interaction between systems	8
Mental health system should be better integrated with housing and employment services	4
The Dept of Corrections and Western State Hospital turn people out with no resources	2
Better mental health services should be provided in local and state jails	1
Felony convictions prevent consumers from accessing housing and employment	1

Employment	10
Create more job opportunities for homeless people that are accessible and appropriate	9
More help for veterans - allow them to go back to work and give back to their community	1
Desired mental health outcomes	7
Continuity of care	5
Homeless people with co-occurring disorders are often pushed from system to system	3
No wrong door for accessing services	2
Long-term changes	2
Everyone should have health insurance	1
Homeless folks would be treated with dignity and respect	1

WASHINGTON STATE MENTAL HEALTH TRANSFORMATION GRANT Public Testimony Summary and Analysis HOMELESSNESS SUBCOMMITTEE

Selected Representative Quotes

Types of services: Recommendations for effective models

(2/17/06 Meeting – Homelessness)

"My point with that being is that one of the – you know, some of these very, very mentally ill people, they're going to have to go to, you know, into the emergency room. Like you're saying, they're going to have to be, you know, hospitalized and locked up and diagnosed and medicated and cost a lot of money to the system. Whereas if we could have – if we could intervene – perhaps, one idea that I think would be a good one . . . would be halfway houses, if there were places where people who have mental illness could go and be safe and live in a group situation and have caretakers there but not – you know, not ordering them around."

Consumer empowerment

(2/17/06 Meeting – Homelessness)

"I just turned 20 last month. I've been doing these meetings for about almost ten years now. Alright? So before I was in middle school, I had to come to these things. Alright? I have not heard one new single thing out of anybody here. I've been hearing these things since, you know, before middle school . . . We don't need new programs. We need to have the consumers teach all the legal people the way we want it to be done, the way it needs to be done, because obviously, it's not working."

Types of services: Services that are needed

(3/10/06 Meeting – Homelessness)

"I tried mental health [treatment], but I had no affordable housing. That's what you've got to do; is get them off the streets in housing first. The problem that I see arising with [outreach workers] is that they have nowhere to put anybody."

Employment

(3/10/06 Meeting – Homelessness)

"[I]t's really tough to go out there and find a job when the last job that you have on an application is nine years ago. And the employer asks you, 'Hey, man, what have you been doing for the last nine years?', 'Oh, living under a tarp down by the river.' It doesn't go over very good, you know, unless you're applying for a survival instructor position or something like that."

Access to services: Problems

(3/10/06 Meeting – Homelessness)

"But, you know, there's problems because a person that's homeless is made to feel like they don't matter at all, like they're not even a human being . . . then the only thing I've got left, the only response I've got left is anger to that. Because I don't have any of the regular means that a person might have to be able to go and try and solve this problem with this state agency. Here's this powerful friggin' agency that's supposed to be there to help us, and is walking all over me,

and here's me, a homeless guy, and I can't afford a lawyer and stuff, if I could find one who would take the case.

Types of services: Services that are needed

(3/10/06 Meeting – Homelessness)

"I think we all, as social workers, I think sometimes we just get lost. We get lost in the pain and suffering you see, you get lost in the bureaucracy, you get lost in the frustration. But if the community can do anything, I think it's simply that supported housing continue, housing for people who have no money."

WASHINGTON STATE MENTAL HEALTH TRANSFORMATION GRANT Public Testimony Summary and Analysis

CO-OCCURRING DISORDERS SUBCOMMITTEE April 3, 2006

Introduction

The current report represents an analysis of the content of public testimony related to the Co-occurring Disorders Subcommittee of the Washington State Mental Health Transformation (MHT) effort. The report provides a summary of statements presented during the public testimony periods of Subcommittee meetings, as well as additional information received by the state MHT team determined by the research team to be relevant to this Subcommittee. These additional pieces of information include public comments received via email, fax, web survey, or handwritten statements, and also relevant feedback submitted from entire agencies or organizations, some of which engaged in their own group processes before compiling and submitting their input.

The analysis presented here also includes information received from other sources during the course of the MHT planning process, such as Regional Support Network (RSN) reports of priorities and transcripts from statewide MHT "Listening Sessions." Finally, statements provided in other Subcommittees' public hearings that were determined to be relevant to the Co-occurring Disorders Subcommittee were included in this analysis.

Method

Across the many sources of data listed above, information received and analyzed typically were responses to a consistent set of 4 open-ended questions posed to individuals statewide:

- 21. Within Washington State, and for all mental health services, public or private, what is working well when addressing the needs of mental health consumers?
- 22. Within Washington State, and for all mental health services, public or private, what is NOT working, creates barriers or fails to provide quality service and support when addressing the needs of mental health consumers?
- 23. What would a "transformed" mental health system look like?
- 24. What outcomes would indicate that the changes in the mental health service systems are creating improved results for consumers?

Data were received from the state MHT team in the form of transcripts from Subcommittee meetings (created by a legal transcription service), reports from RSNs, emails and web surveys forwarded from public constituents, and Adobe Acrobat "PDF" files of handwritten testimony. A team of PhD-level researchers then conducted qualitative analysis of these raw data using a technique described by Marshall & Rossman (1989). First, unique statements were isolated and summarized from all individual testimonials received. Next, categories were created and all

statements sorted by these categories. Third, new categories were created for statements that did not fit the initial categories. Finally, small categories were sorted into primary categories.

Questions about this report can be directed to:

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To increase ease of use and interpretation, a single analysis of all statements was conducted. However, this report also includes a Table with responses broken out by all four questions. The purpose of the report is to provide Subcommittee members and others working on the MHT project a record of all the public feedback received that is relevant to this Subcommittee, organized in a way that allows for observation of the relative amount of testimony provided within each topic area, and discussion of priorities for action.

The current report

The current report consists of three main sections.

- The first section presents an **overview** of the analysis, including data sources and total number of unique statements coded. This section also includes a brief narrative summary of the findings.
- The second section presents the **results of qualitative analysis in detail**. This Table presents unique themes expressed in public testimony for each of the 4 Mental Health Transformation questions, organized by primary and secondary categories. For each unique theme, the number of statements that were found in the data related to that theme is presented. It is hoped that this Table will be a useful reference for the Subcommittee as it reviews the priorities presented by the public for action.
- The third section presents a selection of **direct statements and quotes** from the meeting transcripts and other information received, grouped by major themes.

Acknowledgments

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Sabina Low Sadberry, Ph.D., University of Washington Evans School of Public Affairs

WASHINGTON STATE MENTAL HEALTH TRANSFORMATION GRANT Public Testimony Summary and Analysis CO-OCCURRING DISORDERS SUBCOMMITTEE

Data sources:

- 26. Transcript of subcommittee hearing #1: February 10th, 2006 (Lakewood)
- 27. Transcript of subcommittee hearing #2: February 17th, 2006 (Vancouver)
- 28. Transcript of subcommittee meeting #3: March 9th, 2006 (Seattle)
- 29. Transcript of subcommittee meeting #4: March 16th, 2006 (Moses Lake)
- 30. Relevant statements from Adult Consumers Subcommittee and Children, Youth, and Families Subcommittee meetings
- 31.RSN responses to the 4 Transformation Questions that specifically address this sub-committee's population
- 32. Additional written submissions from individuals, agencies, and organizations statewide

Total Statements coded = 453

Summary of findings

Public testimony relevant to the Co-Occurring Disorders Subcommittee consisted of 453 unique statements coded from 40 individuals who gave testimony at public hearings (or written submissions) as well as additional documents submitted from individuals, RSNs, and other agencies and organizations. Seventy-five statements were coded from responses to the question "What is working well," 135 statements were coded from responses to the question "What is not working well," 196 statements were related to the question about what a transformed system will look like, and 47 comments were coded regarding proposed outcomes of a transformed mental health system.

A brief summary of the results across the four questions is provided below:

- The issue of Collaboration and Integration of services appeared often across respondents. When services collaborate and integrate, they work well. On the other hand, there is not enough cooperation between treatment services and treatment providers, which has been a source of strife for many consumers. This theme was further mentioned as an element of a transformed system. Collaboration seems central to this population since they are being treated for multiple afflictions often by multiple sources. Also, having facilities that served COD clients would help to increase continuity of care.
- Funding is also an important issue for this group. Medicaid, although working very well for those that qualify and receive coupons, seems to be inflexible, difficult to qualify for, as well as not equal in quality of services provided. A recommendation for a transformed system would include funding options other than Medicaid that are also easy to access. A second factor of funding is flexibility. Funding that allows for treatment of MH and of SA works very well when available, but most funding sources are not flexible in

this way. Funding was listed as a barrier for many consumer respondents and would like to see funding not limit care availability or quality of care. The cost of medications, compartmentalized funding, and siloing of funds were also mentioned as barriers to effective treatment.

- COD Specific Treatment is seen as unavailable, particularly to those on government funding. Outpatient COD treatment was further stressed as being difficult to access, if it even exists. This point reflects the comments made about lacking integration of services and also about the inflexible funding issues that do not allow for these types of programs.
- Treatment Service Access is a major problem for this population. Testimonies about seeking COD treatment overwhelmingly illustrated a "ping-pong" effect. For example, the consumer seeks treatment for MH and SA issues and is continually referred back and forth between programs that deal with only one issue. The client is often denied treatment by both providers because of the co-morbid issue. This illustration is also true of co-occurring medical and developmental issues as well. This is a further reflection of the lack of integration of services.
- Issues around Treatment Professionals were: a shortage of professionals trained in the COD field in general, and more specifically, a shortage of psychiatrists.
- Two service needs that were stressed were stable housing and employment programs.
- Access to care, flexible funding options, and integration of services would be indicators of a transformed system. Reduction of stigma, reduction of homeless mentally ill, as well as evidence-based outcome studies in general were mentioned as outcomes of a transformed system.

A full summary of all themes and statements for each of the four questions is presented in the Table on the following pages.

Table 1.
Results of qualitative analysis of public testimony for the Co-Occurring Disorders Subcommittee (N=453 statements total).

Themes	N Statements
What IS working well?	75
Mental Health System (General)	64
Integration/Collaboration/Partnerships btw Programs	7
Access to care is increasing	2
Awareness of changing needs/adaptive	1
Accountability within the system	1
System as whole getting better at COD	1
Mental Health Services (Specific Examples)	26
Clubhouses (work because they are peer-to-peer)	6
Rose House	4
PACT	3
COMET	2
WA Medicaid Integrated Project in Snohomish County	1
Pathways	1
Lifeline Connections	1
NAMI	1
PALS at WSH	1
Seattle MH's deaf program - Gordon House	1
Adoptions Support Programs	1
CODI	1
Ridgefield Living	1
Mental Health Courts	1
Integrated Crisis Center	1
Treatment Practice Approach/Focus	18
Evidence-Based Treatments	3
Outreach	3
Recovery-Focused	2
Early COD Assessment	2
Wraparound approach	2
Employment -Focused	1
Family involvement	1
Grassroots efforts	1
Holistic Approach to COD	1
Best Practices Emphasis	1
Cultural Awareness	1
Treatment Professionals	8
Dedicated Professionals	4
Cross-trained staff	2
CDP's in Assessment Centers	1
Low Employees Turnover Rates	1

Funding	8
From Legislation	3
Funds that are Flexible	1
Medicaid Funding for Axis	1
Non-medicaid Funded Programs/Services	1
Excellent pay and benefits for employees at WSH	1
System works If you have Coupons	1
Training/Education Programs about COD	3

What is NOT working well?	135
Treatment Practices	94
Treatment Providers	25
Shortage of professionals in COD field	8
Not enough Psychiatrists	7
System of who gets employed - too rigid of requirements	3
Not educated about COD	2
Not enough time with patient/family	2
Lack of Quality Assurance	1
Assessment but no recommendation for care	1
Don't Assess both COD conditions	1
Programs	21
Lack of integration and cooperation between services/programs	11
Lack of Services for specific clients/disorders	5
Length of stay too short	2
Not enough peer-to-peer (approach) programs	1
Treatment services for incarcerated	1
Can't get involuntary treatment if needed	1
Consumers	18
Access to Services/Care	12
Takes too long to get treatment after initial attempt	4
Lack of options	2
Hospitals (State, VA, general)	9
Don't have competent treatment	4
Not enough psychiatric beds	3
People stuck there - lack of alternatives	2
Medications	4
Overmedication w/o monitoring of side effects	3
Medications prescribed w/o checking records	1
Other things that are not working well	4
Receiving treatment barriers (general)	5
Lack of COD outpatient treatment	5

Unmanageable Paperwork	3
No uniform COD treatment philosophy	2
Continuity of Care	2
Funding	35
Consumer	20
Compartmentalized Funding (MH and SA separate)	12
Not enough Funding for Medications	4
Lack of resources keep people out who need services	3
No Funding for Evidence-based practices	1
System	14
Lack of flexible funds	8
Treatment by Medicare/Medicaid	6
Services/Programs/Treatment	1
Too much financial decision-making	1
Education/ Training	6
System is not educated about its components	2
	2
Consumers don't know the services/no one to tell them	2
Clinician training in MH and SA issues	1

What will a transformed system look like?	196
Treatment Practices	78
Additional Programs	31
Housing	11
Employment Programs	6
Improved Diversion	4
Post-treatment programs	4
Residential Treatment Centers	3
Transportation	2
Inpatient Facilities	1
Services	29
Regional access to MH services	5
Facilities for COD specifically	4
Wraparound approach	4
Improve Retention Practices	3
Add Recovery Programs	2
Continuity of Care	2
Benefits of Hospitalization	2
Individualized/Tailored Care	2
Hospitalization length too long	1

Peer to peer treatment	1
Expansion of Treatment	1
Needs Assessment for COD	1
Options other than medications	1
Consumers	14
Customer has access to COD services	8
Consumer involvement in delivery of services	4
access to appropriate medications	2
Treatment Professionals	4
Employ trained, certified	1
Difficult to get registered counselor status	1
smaller case loads	1
Contact with Psychiatrists	1
New State MH Model Components	73
Must be Adaptive/Creative/Flexible	5
Reduction of Stigma	5
Streamlined and Simple Access and Procedures	4
Aim for availability of services throughout state	3
Consumer Advocacy	3
Recognize COD	3
Use a known model - don't need to create new one	2
Comprehensive treatment plan	2
Integration/ Cooperation	29
btw services and treatment staff	15
Involving Medical community	8
btw clients and their treatment staff	6
Treatment Focus	17
Outcomes Focused	6
Recovery Focused	3
Consumer-Driven	3
Prevention-Focused	2
Evidence-Based Treatments	2
Early Intervention Focus	1
Funding/ Use of Funds	29
Consumers	17
Individual accountability for client's own funding	6
Funding needs to not limit care availability	4
Funding not tied to Medicare/Medicaid	4
Support People instead of Program	3
Services	10
More Support for clubhouses	3
Evidence-based treatment	2
DVR needs funding	2

For long-term inpatient care	2
Support for psychosocial rehab models	1
Providers	2
Staff Training Funds	1
Increase Staff Salaries	1
Educational and Training Programs	16
Providers	10
Regarding treatment of certain populations	3
Information Sharing	3
Treatment Methods and Practices for COD	2
Research while treatment	2
Consumers	6
Educate Consumers and their families	3
Medications	2
mental health clients in DVR	1

Themes	Number of Statements
What are the OUTCOMES of a transformed system.	47
Consumers	23
decrease in homelessness	4
Increased Customer satisfaction	3
increase in workforce participation (clients)	3
easier access to services	3
decreased time spent in formal MH system	2
decrease in family dysfunction	2
decreased need for acute services	1
decrease in dependency on the MH system	1
increase in lifespan of client's	1
study of what happens to clients who lose services	1
measures of physical health	1
go to school?	1
Services	17
Diversion from Jails	3
Time delays in service delivery	3
Places to go after discharge from hospitals	2
medication side-effect monitoring	2
availability of medication	1
Access to hospitals when necessary	1
WSH downsized - serving fewer people	1
Entire Treatment Spectrum at one facility	1
Equality for COD clients	1

decrease in ER being primary access to care	1
having a larger network of services	1
Evidence-based outcome studies	5
System overall	2
flexible, adaptive responding system	1
cost-benefit analysis	1

WASHINGTON STATE MENTAL HEALTH TRANSFORMATION GRANT Public Testimony Summary and Analysis CO-OCCURRING DISORDERS SUBCOMMITTEE

Selected Representative Quotes

Rose House, Working Well – collaboration/Communication

"And we could have been a help, in that we could have -- if his case manager had called us back when we saw some problems happening, we might have been able to stop him from actually going out there and trying to medicate himself. So our biggest thing is that circle of support that surrounding all of our different colleagues at Rose House actually coming together and being a team rather than separate entities."

Transformed System – State MH Model - Recognize COD's

"If you do not approach a chemical dependency and the psychiatric disorder as a concurrent treatment modality, you will lose that patient."

Need More Collaboration/Communication; Need Education regarding COD

"Doctors prescribing mental health medications without accessing mental health evaluations/ history from clients. Thus the client who is co-occurring ends up with multiple medications from multiple doctors. This in turn costs more money from the tax payers to take care of medical and/or addiction problems exacerbated by the medication mismanagement."

Not working – Lack of Flexibility; Access to Care

"When they do show up to DSHS, often they have a hard time finding the appropriate place. Often they'll show up to say, oh, it looks behavioral so go to mental health division. Mental health division will often say, well, you've got a brain injury so, you know, it's not a mental health disorder, go talk to -- as a -- and they'll tell you this happened before you were 18, maybe it's a mental health disability, go talk to DDD."

Not working – Access to Care; No Treatment for Specific Disorders

"It's just not working. It's just not working for folks with brain injuries and unfortunately for folks with brain injuries, the no wrong door whole policy is missing some punctuation. It's no, wrong door, and that's really unfortunate."

Lack of Options for those without Medicaid or Private Insurances; Access to Care Barriers

"The other way we're serving them is for families that have to give up custody to the state in order to access residential care. My husband and I had to do that. We had to take -- we tried to work with the system. It didn't work. They wouldn't tell us the truth about the services that were available and I finally went down and when I took my 16 year old son to DSHS and I told that little 13 year old woman that was at the door, cute little blond thing, and I said I am not taking him home, and it nearly killed my husband and I to do that."

Lack of Integration/Collaboration; Education needed for Consumers seeking services

"And I was given the impression that all of this was support was working together and people were talking to each other and his probation officer had some idea of who he was

supposed to talk to, and actually, I was the only one that was talking to anybody, as I found out three weeks later. There was no connection."

Lack of Options; Access to Care

"That's pretty much what's wrong with the system, is that there's no coordination. In King County, it's especially frustrating what the lady just said about when I tried to get my son into the community mental health system, as soon as I brought up the fact that he's got chemical dependency programs, he cannot see a counselor until he gets into a drug treatment program. You know, we sort of don't do that. Our private health insurance helped out there more than anything in terms of that, but it wasn't until after he was released from inpatient treatment that he was able to access mental health services at Community Clinic."

WASHINGTON STATE MENTAL HEALTH TRANSFORMATION GRANT Public Testimony Summary and Analysis

CRIMINAL JUSTICE SUBCOMMITTEE April 3, 2006

Introduction

The current report represents an analysis of the content of public testimony related to the Criminal Justice Subcommittee of the Washington State Mental Health Transformation (MHT) effort. The report provides a summary of statements presented during the public testimony periods of Subcommittee meetings, as well as additional information received by the state MHT team determined by the research team to be relevant to this Subcommittee. These additional pieces of information include public comments received via email, fax, web survey, or handwritten statements, and also relevant feedback submitted from entire agencies or organizations, some of which engaged in their own group processes before compiling and submitting their input.

The analysis presented here also includes information received from other sources during the course of the MHT planning process, such as Regional Support Network (RSN) reports of priorities and transcripts from statewide MHT "Listening Sessions." Finally, statements provided in other Subcommittees' public hearings that were determined to be relevant to the Criminal Justice Subcommittee were included in this analysis.

Method

Across the many sources of data listed above, information received and analyzed typically were responses to a consistent set of 4 open-ended questions posed to individuals statewide:

- 25. Within Washington State, and for all mental health services, public or private, what is working well when addressing the needs of mental health consumers?
- 26. Within Washington State, and for all mental health services, public or private, what is NOT working, creates barriers or fails to provide quality service and support when addressing the needs of mental health consumers?
- 27. What would a "transformed" mental health system look like?
- 28. What outcomes would indicate that the changes in the mental health service systems are creating improved results for consumers?

Data were received from the state MHT team in the form of transcripts from Subcommittee meetings (created by a legal transcription service), reports from RSNs, emails and web surveys forwarded from public constituents, and Adobe Acrobat "PDF" files of handwritten testimony. A team of PhD-level researchers then conducted qualitative analysis of these raw data using a technique described by Marshall & Rossman (1989). First, unique statements were isolated and summarized from all individual testimonials received. Next, categories were created and all statements sorted by these categories. Third, new categories were created for statements that did not fit the initial categories. Finally, small categories were sorted into primary categories.

Questions about this report can be directed to:

Eric J. Bruns, Ph.D., University of Washington Division of Public Behavioral Health and Justice Policy ebruns @u.washington.edu — 146 N. Canal Street, Suite 100, Seattle, WA, 98107 — 206-685-2085

To increase ease of use and interpretation, a single analysis of all statements was conducted. The information presented here combines responses to all four questions into a single summary of all testimony received. The purpose of the report is to provide Subcommittee members and others working on the MHT project a record of all the public feedback received that is relevant to this Subcommittee, organized in a way that allows for observation of the relative amount of testimony provided within each topic area, and discussion of priorities for action.

The current report

The current report consists of three main sections.

- The first section presents an **overview** of the analysis, including data sources and total number of unique statements coded. This section also includes a brief narrative summary of the findings.
- The second section presents the **results of qualitative analysis in detail**. This Table presents unique themes expressed in public testimony, organized by primary and secondary categories. For each unique theme, the number of statements that were found in the data related to that theme is presented. It is hoped that this Table will be a useful reference for the Subcommittee as it reviews the priorities presented by the public for action.
- The third section presents a selection of **direct statements and quotes** from the meeting transcripts and other information received, grouped by major themes.

Acknowledgments

Data analysis for the Mental Health Transformation Public Testimony Summary and Analysis Reports was conducted by:

Suzanne E. Kerns, PhD ABD, Eric J. Bruns, Ph.D., Phoebe Mulligan, and Justin D. Smith, University of Washington Division of Public Behavioral Health and Justice Policy Maria Monroe-DeVita, Behavioral Tech Research, Inc.

Sabina Low Sadberry, Ph.D., University of Washington Evans School of Public Affairs

WASHINGTON STATE MENTAL HEALTH TRANSFORMATION GRANT Public Testimony Summary and Analysis CRIMINAL JUSTICE SUBCOMMITTEE

Data sources:

- 33. Transcript of subcommittee hearing #1: February 7th, 2006 (Kent)
- 34. Transcript of subcommittee hearing #2: March 13th, 2006 (Yakima)
- 35. Relevant statements from Co-occurring Disorders and Children, Youth, and Families Subcommittee meetings
- 36. Feedback submitted from RSNs statewide
- 37. Additional written submissions from individuals, agencies, and organizations statewide

Total Statements coded = 179

Summary of findings

Public testimony relevant to the Criminal Justice Subcommittee consisted of 179 unique statements coded from 38 individuals who gave testimony at public hearings (or written submissions) as well as additional documents submitted from individuals, agencies, and organizations. These 179 statements were sorted into 10 main categories or themes. The two categories into which the most statements were coded was access to services (42 statements), including barriers to care and possible solutions; and commentary about existing services or service types (40 statements), including services that are working well for this population, services that are needed, and issues about cultural competence in service delivery. Input was also received about outcomes that should occur for this population and outcomes that should be tracked (28 statements). Testimony was also received about transitions (16 statements) and the cyclical nature of the criminal justice system and treatment within it (15 statements). Additional categories included financing issues, employment, education and training, and collaboration between systems. A summary of these results is presented below.

Services that were recommended included services that were evidence-based, peer support services, family focused services, and the continuation and development of Mental Health and Drug courts. For youth specifically, prevention programs were recommended. Continuity between services provided in the jail and ongoing and transition care is essential in helping individuals succeed out in the community. Support for family members and family preservation services was emphasized, as many people who are incarcerated lose contact with their children. Culturally specific services, such as bilingual/bicultural programs, were also recommended given the disproportionate confinement of people of color. Programs that work with dually diagnosed offenders are essential, as that is a group that has difficulty accessing services.

With specific regard to the **legal system**, it was indicated that the process of evaluating mentally ill people often kept them in jail longer than a guilty plea would have, which constitutes unfair treatment of mentally ill individuals. **Police officers** were also a large focus, with training on working with mentally ill offenders suggested, as well as training to work with juveniles more effectively. **Lawyers**, especially defense lawyers, should receive additional training in working with mentally ill defendants. **Service providers** of all types should be trained to recognize symptoms and make appropriate referrals. Additionally, participants suggested that there are

relatively few options for mentally ill individuals in **crisis** other than jail; this is unacceptable and services and supports should be expanded to meet the needs of a large population.

Education of police officers, those involved in the legal system, and the public in general regarding the actual risks posed by mentally ill offenders is necessary. This population needs greater access to **educational and employment opportunities**, which also speaks to the importance of assistance and discharge planning during the transition from jail or state hospitals to the community. **Housing** resources are necessary in order to facilitate this transition and provide offenders with the greatest chance of success. The nature of the mental health and criminal justice systems is very cyclical, as most offenders are only treated for their mental illness when they have reached a severe stage and committed a crime. All individuals should have access to mental health services early on, with competent assessment and evaluation procedures being in place within other systems (i.e., schools, community providers). Specifically, when children are assessed, the requirements for treatment are so high (with the new standard for eligible diagnoses) that most often they do not receive the necessary services.

Currently, there is no consistent set of measurable **outcomes** that is defined for evaluating the success of the criminal justice system. There were many proposals for how to evaluate systems, including **consumer satisfaction** surveys, a decline in the incarceration and **re-offending rates** of mentally ill youth and adults, reduction in suicide rates (both while incarcerated and in the community), and reduction or complete remission of symptoms. A specific concern in line with disproportionate confinement of people of color is that access to services would be equal across the board, regardless of race.

A full summary of all themes and statements within each theme is presented in the Table on the following pages.

Table 1.
Results of qualitative analysis of public testimony for the Criminal Justice Subcommittee (N=179 statements total).

Themes	N Statements
Types of Services	40
Recommendations for effective models	22
Drug and Mental Health courts	5
The Clubhouse system provides a place to learn skills, find community and services	4
Family Preservation Services	4
Use best practices or evidence-based models	4
Prevention programs for youth	3
Drug/Alcohol programs at Purdy Women's facility	1
Peer support teams	1
Services that are needed	16
Services (i.e., housing) for offenders, especially those who are dually diagnosed or are sex offenders	4
Services in rural areas, not spread evenly throughout the state	2
Support for family members	2
Improved mental health services in the jails	2
Community based services	2
There are not enough services for juveniles at any point in their system involvement	1
Special accommodations for clients with FAS/FAE	1
Crisis repsonse services	1
Adolescent psychiatric services	1
Culturally specific services	2
Bilingual/bicultural treatment providers	1
Treatment services would be strength-based and family-centered and would respect the patient's cultural heritage	1
Interaction with multiple systems	5
Common for first interaction with a system to be with the police	2
Lack of system integration	2
Prison is currently considered less restrictive than a psychiatric unit	1
Employment opportunities essential to recovery	5
Those who leave jail should be employed and moving toward their goals	3
Jobs are very difficult to find if someone has a felony record	2
Education	9
General public and professionals need to be educated on actual risks posed by mentally ill offenders	7
Need mandatory education for youth on neuroscience and stigmas	1

Increase educational access	1
Transitions	15
Gap between release from jail and community services	5
More housing/group homes for people transitioning out of jail or state hospitals	3
Better discharge planning	3
Each person would have an advocate to help them transition between systems	2
Healthy independence should be supported by the system	1
More people need to be in the recovery stage	1
Cyclical nature of the system	16
Address the cyclical nature of the MH and CJ systems by providing ongoing support	7
Need accessible and inexpensive screening to identify people who need services early on	4
The same people come through the system because they have to reach a serious stage to be noticed	2
Need an information management system so no one gets lost and progress can be measured	2
Agencies will begin referring clients back and forth	1
Financing issues	11
For individuals	5
Youth who are incarcerated for more than 30 days lose Medicaid benefits	2
Low-income people are most greatly affected by the funding cuts	1
Provide sliding scale fees for services	1
Kids without medical coupons have difficulty accessing services	1
For programs	6
Programs need more funding to provide sufficient services	2
Funding for mental health services is being directed toward the adult system, rather than the juvenile system	1
There is a constant ebb and flow of funding	1
Statewide RSN system where benefits do not change by region	1
Competition for funding between adult and juvenile systems	1
Access to services	42
Problems	28
The inability of providers to get timely evaluations of mentally ill offenders Jails have become synonymous with "crisis intervention"	12 5
Police officers are often left with few options of where to take mentally ill people for services, especially after business hours	3
Individuals not receiving care in a timely manner	3
The diagnoses that qualify children for sufficient services are too limited and do not allow for early intervention	2
Insufficient staffing in jails and state hospitals may mean that mentally ill offenders receive a lower standard of treatment than non-mentally ill offenders	2

The traditional forms of services are not meeting the mental health needs of	1
youth and their families	'
Solutions	14
Better continuity of care	6
Access to mental health care without having to go through the criminal justice system.	3
Focus on rehabilitation rather than punishment	2
Crisis intervention team made up of all necessary professionals	1
General services should be increased in order to have an effect on the criminal justice population	1
People who are in jail and are mentally ill would spend their time in the custody of a state hospital – rather than in jail – while they awaited trial and/or evaluation	1
Outcomes	28
Measurement of outcomes	7
Evaluations of systems should be conducted to determine consumer satisfaction	3
No current outcome that is defined and measurable	1
There is a measurable reduction in the level of stigmatization and irrational fear around mental illness as measured by objective surveys	1
Need to conduct an assessment to determine whether people can make their own decisions	1
Make sure the new process is sustainable	1
Statistical outcomes showing positive changes	21
Decline in incarceration and a reduction in re-offending rates of mentally ill youth and adults	14
Reduction in suicide rates	2
Lessen the disproportionate representation of minorities in the criminal justice system	1
Charges would be lower if the person was mentally ill	1
People would get out of prison sooner because they have received treatment	1
Provide people of color with the same opportunities to receive mental health services	1
Reduction or complete remission of symptoms	1
Training	8
Police officers would be trained to work with mentally ill offenders	5
More training for lawyers working with mentally ill offenders	1
Police officers specifically trained to work with juveniles	1
Service providers of all types are trained to recognize symptoms and appropriately refer clients to services	1

WASHINGTON STATE MENTAL HEALTH TRANSFORMATION GRANT Public Testimony Summary and Analysis CRIMINAL JUSTICE SUBCOMMITTEE

Selected Representative Quotes

Education

(2/7/06 Meeting – Criminal Justice)

I think we need to have "a better understanding by the general public, advocates, consumers, and professionals of the actual risks posed by mentally ill offenders, which should hopefully ensure proper access to services based on facts rather than stigma."

Access to services: Solutions

(3/13/06 Meeting – Criminal Justice)

"[A transformed system] would be much more seamless. The whole corrections-based mental health would be a lot more seamless so that we could do a better job of possibly helping a kid before the adjudication takes place so that we don't ruin his or her criminal history forever."

Access to services: Problems

(3/13/06 Meeting – Criminal Justice)

"[Defense attorneys] don't want to advise their client to plead guilty, because perhaps they're not guilty under the law, or they can't communicate well enough with their attorney to be able to participate in their defense. Yet, if they sit in jail waiting for the evaluation to show that they're not guilty, they end up in jail longer than if they would have just plead guilty. So it's a very difficult situation that the defendants are in."

Access to services: Problems

(3/13/06 Meeting – Criminal Justice)

"A lot of the diagnoses that were brought down [based on the revisions to service access criteria] . . . like ADHD, Disruptive Behavior Disorder, Oppositional Defiance Disorder, Conduct Disorder. So if we have a child, or a teen, coming in with this screening who meets that criteria, but they're not at risk of being out in the street, they're not having to be hospitalized, they don't meet that criteria, they cannot be accessed for services."

WASHINGTON STATE MENTAL HEALTH TRANSFORMATION GRANT Public Testimony Summary and Analysis

PUBLIC INPUT April 6, 2006

Introduction

The current report represents an analysis of the content of public testimony related to the Washington State Mental Health Transformation (MHT) effort. The report provides a summary of statements received by the state MHT team. These pieces of information include public comments received via email, fax, web survey, or handwritten statements, and also relevant feedback submitted from entire agencies or organizations, some of which engaged in their own group processes before compiling and submitting their input.

Method

Across the many sources of data listed above, information received and analyzed typically were responses to a consistent set of 4 open-ended questions posed to individuals statewide:

- 29. Within Washington State, and for all mental health services, public or private, what is working well when addressing the needs of mental health consumers?
- 30. Within Washington State, and for all mental health services, public or private, what is NOT working, creates barriers or fails to provide quality service and support when addressing the needs of mental health consumers?
- 31. What would a "transformed" mental health system look like?
- 32. What outcomes would indicate that the changes in the mental health service systems are creating improved results for consumers?

Data were received from the state MHT team in the form of reports from agencies or programs, emails and web surveys forwarded from public constituents, and Adobe Acrobat "PDF" files of handwritten testimony. A team of PhD-level researchers then conducted qualitative analysis of these raw data using a technique described by Marshall & Rossman (1989). First, unique statements were isolated and summarized from all individual testimonials received. Next, categories were created and all statements sorted by these categories. Third, new categories were created for statements that did not fit the initial categories. Finally, small categories were sorted into primary categories.

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Eric J. Bruns, Ph.D., University of Washington Division of Public Behavioral Health and Justice Policy ebruns@u.washington.edu – 146 N. Canal Street, Suite 100, Seattle, WA, 98107 – 206-685-2085

To increase ease of use and interpretation, a single analysis of all statements was conducted. However, this report also includes a Table with responses broken out by all four questions. The purpose of the report is to provide those working on the MHT project a record of all the public feedback received, organized in a way that allows for observation of the relative amount of testimony provided within each topic area, and discussion of priorities for action.

The current report

The current report consists of three main sections.

- The first section presents an **overview** of the analysis, including data sources and total number of unique statements coded. This section also includes a brief narrative summary of the findings.
- The second section presents the **results of qualitative analysis in detail**. This Table presents unique themes expressed in public testimony for each of the 4 Mental Health Transformation questions, organized by primary and secondary categories. For each unique theme, the number of statements that were found in the data related to that theme is presented. It is hoped that this Table will be a useful reference for the Subcommittee as it reviews the priorities presented by the public for action.
- The third section presents a selection of **direct statements and quotes** from the meeting transcripts and other information received, grouped by major themes.

Acknowledgments

Data analysis for the Mental Health Transformation Public Testimony Summary and Analysis Reports was conducted by:

Suzanne E. Kerns, PhD ABD, Eric J. Bruns, Ph.D., Phoebe Mulligan, and Justin D. Smith, University of Washington Division of Public Behavioral Health and Justice Policy Maria Monroe-DeVita, Behavioral Tech Research, Inc.

Sabina Low Sadberry, Ph.D., University of Washington Evans School of Public Affairs

WASHINGTON STATE MENTAL HEALTH TRANSFORMATION GRANT Public Testimony Summary and Analysis PUBLIC INPUT

Data sources:

38. Handwritten Statements in "PDF" format

39. Web Surveys

40. Faxes

41. Emails

42. Other forms submitted to the MHT team for analysis.

Total Statements coded = 2261

Summary of findings

Individual public testimony covering all populations in the mental health system consisted of 2261 unique statements coded from 248 individual sources of input. Raw data included submissions of testimony via hand-written submission, email, fax, as well as additional documents received from agencies and organizations that could not be present at specific Subcommittee meetings or other public hearings.

Three hundred and thirty-five statements were coded from responses to the question "What is working well," 751 statements were coded from responses to the question "What is not working well," 821 statements were related to the question about what a transformed system will look like, and 354 comments were coded regarding proposed outcomes of a transformed mental health system.

A brief summary of the results across the four questions is provided below:

- Funding in general was noted many times by consumers and providers. A general lack of funding exists in the mental health system. Providers do not have the funding to meet the needs of the consumers and many consumers in need do not qualify for Medicaid and do not have the ability to pay for services. Inflexibility is a key funding issue for consumers and providers. Consumers' treatment is often dictated by what funding they have rather than what treatment they need, while providers are forced to only provide treatment to those who qualify for that program's services and not based on the needs of the consumer. A transformed system would have more flexible funding options and the funding would follow the consumer not be restricted to the programs and services.
- Medicaid funding was a major topic of discussion. The system is works better for individuals who qualify for Medicaid, but the eligibility requirements for Medicaid are viewed as being too strict, which makes access for other consumers very difficult. Access to care for non-Medicaid eligible consumers is one of the major issues of the current system. One remedy suggested is to make access easier by having more flexible funding sources other than Medicaid.

- Access to care in general was noted as a barrier to care in the current system. Access for non-Medicaid and non-private pay, access to appropriate medications, access to a psychiatrist or other doctoral level therapist, and access to services in rural areas were the most mentioned. If a person does manage to qualify for services, receiving timely treatment was often difficult. The time from referral to assessment and then to treatment itself are often lengthy. For those who cannot access the system or those who do not receive timely treatment, the only option is often primary care physicians or the ER. This costs a lot of money and providers are not trained to handle mental health in these facilities, so need for treatment often is often supplanted with crisis de-escalation without follow-up or referral leading to a return to the ER. One major comment about access from is that there is never enough resources to meet the demands, thus, service providers are forced to turn away many people who are not in crisis. Consumers commented that crisis care was readily available but that follow-up often was not due to lack of resources.
- Providers and consumers alike mentioned that the system currently has too much bureaucracy, unmanageable paperwork requirements, and too many regulations that are constantly changing and often conflicting. Providers say that paperwork requirements cause them to spend less time with clients because of the time it takes to complete paperwork. Consumers also said that the paperwork at intake and when transferred to other programs was excessive. Consumers often opted out of services before they even began once they saw the amount of paperwork required to get in to the system. An MIS system for providers to share client information, a uniform policy and regulatory system, as well as less restriction on client privacy were all mentioned as ways to remedy this issue in the transformed system.
- Integration and Collaboration of services and between individual professionals was noted as not being done efficiently or often and was noted as a key component of a transformed system. Transfers and referrals were often not smooth, had immense paperwork demands on both the client and the provider, and often took very long to achieve while, in the mean time, the client was not receiving treatment. Integration in the transformed system would have much more integration between programs and services. Primary care and mental health would be in one facility, substance abuse treatment and mental health services would be combined, and different services, such as clubhouses and mental health programs would work together. There would also be increased communication between providers to streamline referrals and to aid in the treatment of clients being served in multiple settings for co-occurring afflictions.
- Mental health in the education system was mentioned often as a component needed in an integrated system. Ideally, educators would be trained to recognize mental health issues and would then have a network to refer these children for assessment and treatment if necessary. This prevention/early intervention approach was mentioned as a way to cut long-term costs in later mental health treatment if the problems could be identified and lessened early on.

- Mental Health and the Justice System was a common topic. Officers are often asked to make a judgment call about a mental health issue of a suspect often without proper knowledge of mental health and often without options for diversion even if they suspect mental illness. Once incarcerated, mentally ill offenders do not have much access to treatment. The offender either serves time or is released (often mentally ill offenders are released early because of their issue) and because there was no treatment or assessment, they return to the streets instead of a mental health program and more often than not, they become repeat offenders and the cycle continues. The education of diversion from prison and training on the part of the officers and the criminal justice system was noted as improving, but is still an area of concern that needs to change.
- Services Needed. Improvements and additional availability of specific services and program components were frequently cited. Housing was the most frequently mentioned. Day treatment centers and day programs, more clubhouses, drop-in centers, respite, employment services, and wraparound programs were also mentioned. Transportation for mentally ill consumers was seen as necessary so that they could get to appointments.
- Treatment Focus. The way to approach treatment and mental illness was a frequent focus of testimony. The order of frequency of nominations was as follows: Prevention-Focused, consumer-driven, family integration, recovery-focused, culturally aware services, early intervention approach, evidence-based treatments, strengths-based approach, and also a number of others that were less frequently mentioned.
- In regards to **Treatment Professionals**, there is an overall lack of quality providers especially psychologists, psychiatrists, and case managers. Reasons for these issues are the low pay for mental health staff, low job satisfaction, high case loads, and unmanageable "red tape" causing turnover that affects the overall quality of treatment.
- Stigma was mentioned often as a problem. Educational efforts directed at the community aimed at the reduction of stigma were mentioned as a needed component and was also considered a marker of a transformed system.
- Regional Discrepancies were mentioned many times. Consumers and providers in smaller, rural areas are experiencing a lack of options for treatment as well as the inequality of government funding to smaller areas that increases the lack of options. Consumers must travel great distances to get to treatment centers and then may have to go even further to get services that actually fit their need. Equality in all areas of the state would be an indicator of a transformed system.
- Outcomes The most often mentioned outcomes of a transformed system were: Fewer mental health issues encountered in the criminal justice system, fewer mental health in ER and in primary care facilities, reduced homelessness of mentally ill individuals, increased consumer satisfaction, easier access to care, higher employment rates for mentally ill, reduction of stigma, decreased recidivism, and reduction of crisis situations, as well as many others.

A full summary of all themes and statements for each of the four questions is presented in the Table on the following pages.	

Table 1.
Results of qualitative analysis of public testimony included in the Additional Public Testimony report (N=2261 statements total).

Themes	N Statements
What is working well?	335
Mental Health Services	152
General Services/Program Types/Facilities	110
Clubhouses	21
Peer-to-Peer Programs	12
Immediate Crisis Services are Available When Needed	10
Community Mental Health Centers	9
Law Enforcement Can Easily Transfer Mental Health Issues to a MHP	6
Residences/Housing/Transitional Housing	6
Access to Care is Improving but Not Necessarily "Working Well"	6
Mental Health Services in Jails is Better	6
Vocational and Educational Programs	5
Triage Centers	5
Mental Health System and Services in General	5
Transitional Services after Leaving Jail	4
Private Mental Health Services are Great but Very Costly to the Consumer	4
Quality of Care Continues to Improve	3
Outreach in Smaller Communities	2
Vocational Services	2
Involuntary Treatment Act	2
Smooth Transitions to Hospitals When Beds are Available	1
Co-Located Mental Health and Primary Care Facilities	1
Mental Health Services/Programs Specific Examples	57
Mental Health Court	6
NAMI	6
Crisis Hotlines	5
Harvest House	5

Themes	N Statements
Ombudsmen Program	4
Rainbow House	4
Catholic Family Services	3
State Hospital Access to Services	3
FPS	3
Dr. Court	3
MIKA	2
PCAP	2
EPIC	2
YAR	2
Safety Centers	1
PACT	1
Ridgefield Living	1
Purdy Women's Correctional Facility	1
DMIO	1
Day Treatment at WSH	1
Emergency Preparedness and Mental Health	1
Treatment Practices	99
Treatment Professionals	48
Dedicated and Committed People	17
Well-Trained and Knowledgeable Providers	9
Flexible and Willing to Work with Clients	6
Access to Psychiatrists for Consultation	5
Mental Health Professionals Available in Emergency Room to Assist Physicians	5
Positive Attitudes and Collaboration with Other Agencies	4
Culturally Diverse Service Providers	2
General Practices	16
Consumer-Driven Treatment	6
DBT Really Does Work	3
Access to Medications (if you can get to a psychiatrist)	2

Themes	N Statements
Transitional Services to Keep People from Being Homeless	2
Immediate Access to Care for Children in Foster Care Network	2
Increased Time Spent with Direct Care Providers	1
Integration and Collaboration of Resources	11
Improving	11
Integrated Programs (not just mental health issues)	3
Treatment Focus/Emphasis	6
Recovery-Based Approach	3
WRAPAROUND Approach	3
Funding	36
If you have Medicaid or Private Pay, Services Working Well	17
State Funding has Increased	10
Capitated Funding is Stable Stream for Agencies	6
Efforts to Find New, Flexible Funding Streams	3
Nothing Is Working	25
Miscellaneous Comments	12
Ads About Mental Health in Newspapers	3
Depression Ads on TV	3
State has Begun to Show Support for Mental Health	2
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Ombuds and Providers Work Well Together	1
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Themes N Statements

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Cannot be Individualized/Tailored	4
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Always Changing Because of Unpredictable Funding	3
Value-Based Instead of Scientifically-Based Treatments	3
Commitment Procedures and Practices Do Not Work	2
Treatment in State Hospitals Not Quality	2
Discharge Process Too Difficult and Takes Too Long	2
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Themes	N Statements
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Children and Families Have the Hardest Time Getting Treatment	3
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Increased Flexibility/Adaptability	4
Stop Forcing Medications and Psychiatry on People	3
Ongoing Review and Case Management	2
All Agencies Have Access to SAHMSA Resources	1
Treatment Professionals	55
More Counselors/Case Workers	15

Themes	N Statements
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Lower Case Loads	9
MIS System for RSN's and Other Providers to Streamline Transitions	8
Need for Bilingual/Multicultural Counselors and Professionals	4
Professionals Trained to Treat Co-Occurring Disorders	4
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Greater Array of Services/Choices	6
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Themes	N Statements
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More Counseling Services	2
Parenting Education	1
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Prevention-Focused	16
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Family Counseling Services/Family Integration	10
Recovery-Based	9
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Evidence-Based Treatment	9
Strength-Based Approach	6
Age Awareness/No Neglecting of Younger or Older Populations	6
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Funding/ Use of Funds	76
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Increased Pay for Mental Health Staff	13
More Funding Across the Board	11
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Themes	N Statements
Money Follows the Client Not the Agency/Programs	6
Stable	5
Do Not Lose Funding in Jail	5
Medication Support	2
College Campus Mental Health Centers	1
More Informed Provider Network	1
Funding for Post-Partum Depression Extended	1
Go Beyond the Medicaid Minimum and Provide What is Actually Needed for Success	1
Funding for Immigrants to Get Mental Health Services	1
More Funding for Special Education Program In Schools	1
Training and Education	65
Consumer-Focused Education Efforts/Integrated Education into Existing Programs	13
Educate the Community (general public, schools, etc.)	11
Educate Police Officers About Mental Illness to Aid Diversion	11
Staff Trainings	11
Treatment Professionals in General	7
Social Skills Training for Consumers	5
Medications, How to Get Them, Side Effects (to the consumer)	3
Train the Families About Mental Health and How to Help	2
Mental Health Professionals About Chemical Dependency and Vice-Versa	1
Conferences About Holistic/Other Alternatives to Current Treatment	1
Entire MH System	34
Consistent Policies and Procedures (not different for each RSN)	11
Stability	8
Regional Services - Closer to Home, More Accessible	6
No RSN Network	5
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State Would Actually Support Mental Health System	2

Themes	N Statements
Themes	N Statements
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Fewer Mental Health Cases in Justice System/Less Jail Time for Mental Illness Issue	40
Fewer Mental Health Hospital Visits/Hospital stays	33
Reduced Homelessness	27
Consumer Satisfaction Increased	25
Increased Access to Care	22
Employment Rates Following Treatment	19
Reduction of Stigma	18
Decreased Recidivism	11
Greater Access to Medications and How to Pay for Them	9
Reduce Crisis Situations	7
Home and Social Stability After Release	6
Fewer Involuntary Commitments/Incarcerations for Mental Health Issues	6
Consumers Set Their Own Goals	5
Use the GAF as a Result Assessment	5
Reduction of Suicide Rates	5
Consumer Representation in Government	4
More Interaction with Psychiatrist	4
Returning to/Seeking Further Education After Treatment	3

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Reduction of Suicide Rates	5
Consumer Representation in Government	4
More Interaction with Psychiatrist	4
Returning to/Seeking Further Education After Treatment	3
Fewer People in Acute Care Situations	2
School Children are Less Disruptive and Attend School More Often	2
Better Educational Performance After Treatment (mainly children)	1
Decreased Deaths for Homeless Mental Illness	1
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Timely Treatment	13
Higher Provider Job Satisfaction	9

Themes	N Statements
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Well-Trained Workforce	8
Smaller Case Loads	7
Better Retention rate	6
At-Home Treatment Services	6
24 Hour Availability	3
Strength-Based	2
More Regular Mental Health Treatment	2
Better Assessments	1
Less Diagnosis Handed Out	1
Transitional Services and Supervision of Transitions	1
Need for Services is Met Not Higher Than Those Provided	1
Funding	31
Treatment for those non-Medicaid	9
Flexible funding	6
Adequate stable funding	6
If you qualify, you get quality, timely treatment	5
Reduced Administrative Overhead	3
Clients do not lose funding if they go to jail	1
Decreased Cost per Client/Cost per Service Hour	1

WASHINGTON STATE MENTAL HEALTH TRANSFORMATION GRANT Public Testimony Summary and Analysis ADDITIONAL PUBLIC INPUT

Selected Representative Quotes

System as a Whole Working Poorly

"As hinted in the president's commission report, there is something fundamentally wrong with a system that takes the most complicated medical conditions such as schizophrenia, borderline personality disorder, bipolar affective disorder, addictions, etc. out of the health system and puts them in state or local government bureaucracies with very limited budgets. It is hard to imagine a Division of Cancer Treatment in DSHS where patients diagnosed with cancer have to leave their medical centers and enroll in special cancer agencies in order to get their cancer care staffed by providers with less training and for drastically less money than they would have gotten if they had been diagnosed with heart disease and stayed in the medical system."

Access to Care – Quality of Care

"What is not working in our community is lack of access for people needing services, lack of services, lack of services that properly address mental illness. We have seen emphasis on behavioral changes for individuals, behavioral changes for family, behavioral changes for children without in some cases adequate diagnosis, treatment plan, case management, medication management. And what this translates to is less than adequate treatment of a significant biochemical imbalance of the brain."

Access for Non-Medicaid Qualifiers

"Access to services and treatment for those without Medicaid is very difficult and not equal – some RSN (KingCo in particular) has virtually no capacity to provide outpatient health services if the person does not have Medicaid."

Too Many People Receiving Treatment by Primary Care Physicians and ER

"Many low-income people end up seeking and receiving mental health services through their primary care providers at community health centers, because that is the only avenue available to them. Family practice physicians, nurse practitioners and physician assistants are stretched beyond their scope of practice to prescribe and monitor psychiatric medications, because there is no where else for patients to receive this service."

Treatment Providers in Jails – Transitions Out of Prison in Place

"If there were ADATSA counselors at the prisons, then the offenders could go directly from prison to inpatient treatment centers. Maybe the CD treatment center has a discharge planner. The folks who need inpatient CD treatment the most are the mentally ill offenders who continue to re-offend. These offenders are homeless, do not have SSI or a medical coupon, are committing crimes to continue their drug habits. Why doesn't someone stop this awful cycle by allowing ADATSA counselors into the prisons?"

Treatment Providers in Jails

"How someone becomes mentally disabled creates the structure and method in which they are treated. Crime caused by mental disability is still crime and clearly must be addressed. Corrections facilities should consider being treatment facilities as well as part of total corrections and education programs."

Integration and Collaboration

"The RSN and non-RSN parts of the mental health service structure would be well integrated. Mental health issues are very interrelated. Homeless mental health is tied to chemical dependency, life skills, and Veterans issues – they cannot be looked at in isolation. The structure of service delivery is not nearly as well integrated as the nature of the problems."

Integration and Collaboration – Communication between Providers

"There is no commonly accepted framework or language for describing mental health services delivery structure that efficiently and effectively communicates what is available and where their are gaps."

Integration and Collaboration

"I see the need for the state funded mental health team to be integrated with the local health care teams. I do not think that having only a freestanding mental health facility is going to be adequate. Most of the patients that are seen for mental health disorders are seen because of co-morbidities, preventive health measures, or other reasons that they come to a health care provider. Unless there is a significant amount of integration and coordination of this care, we will always be battling inadequate access, inadequate supply due to the lack of capacity planning, therefore running the risk of either inadequate capacity, which we have now, or duplication of services elevating the direct cost of care unnecessarily."

Too Much Bureaucracy – Administrative Costs Detract from Treatment

"The state and federal governments continue to increase administrative burden in managing the system, much of which does not contribute of more or better care for consumers. These increased costs have not been covered by increased revenue, but instead there is pressure to reduce administrative expenses."

Unmanageable Paperwork Requirements

"In addition, the paperwork requirements for therapists providing services are so daunting that they cannot see many clients. The face-to-face percentage requirements at our agency are kept at 50% specifically because of the paperwork. Having worked in other states, I know that I could see many more clients than 20 out of a 40 hour work week. So, we could provide services to more people if the paperwork was less. What happens is that therapists get burned out quickly because of the paper demands and then the low pay. This agency has difficulty maintaining quality counselors due to the extremely low pay. I, myself, could qualify for this county's sliding fee scale because of my low income."

Unmanageable Paperwork - Only Serve in Crisis - Staff Wages - Staff Turnover

"Given the limited funding of public mental health services, caseloads (at least in King County) are incredibly high and the paperwork work load so overwhelming that many patients with severe illnesses are seen as little as monthly and often only to complete needed paperwork. Clinical care is often provided only when a client calls in crisis leading to chaotic schedules for clinicians and chaotic treatment ebbing and flowing for clients. Case managers are paid very little money. With the above job stress and lack of training there is such frequent turnover that it appears that many provider agencies don't even try and invest in training as their staff are likely to leave in 4-12 months. Such turnover for clients with severe illnesses lasting years to decades is unconscionable."

Increased Treatment Staff Wages

"Funding would be consistent with the desired educational levels of service providers and staff members would be treated as professionals, in terms of financial compensation and basic respect. The federal government and the state would stop treating providers of social and human services as second class citizens."

Funding Causes Program Instability – Need Stable Funding Streams

"There continues to be a fickle system of funding which ensures instability in programs that provide critical services. Programs are forced to continually shift and change due to an unpredictable funding base."

Lack of Funding and Resources

"Lack of adequate funding for public services. In outpatient work this means frequency & duration of treatment is not based truly on client needs and clinical assessment but on level of care guidelines geared to manage scarce resources. It means that a population who have experienced trauma of many kinds, but particularly around human attachment, are re-traumatized again and again because they can be provided only with crisis services, and no durable trustworthy bonds. It means therapists are stressed by doing harm to already vulnerable clients."